Describing an iceberg from a glimpse of its tip: a summary of the literature on achievements in Aboriginal and Torres Strait Islander health

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Preface

Attempting to document achievements in Aboriginal and Torres Strait Islander health by reviewing the literature is a bit like trying to describe an iceberg from a glimpse of its tip.

Like an iceberg, the bulk of achievements in Indigenous health are not within view, as they have never been written up for publication in the literature (even the so-called grey literature). As with most health (and other) programs, many practitioners have implemented successful strategies based on well-established principles without considering the need to publish the results. Particularly if they are based on programs proven to be successful in other contexts, their implementation in an Indigenous context is not even subject to formal evaluation. People working in the area of Indigenous health have no doubts about the success of many programs, and have never thought it necessary to spend time on the sometimes demanding task of writing them up for publication. However, even though there may not have been a need to 'prove' the achievement by publication, there really is a need to share the knowledge of successful programs with other people in other parts of Australia. The sharing of knowledge is a key element of knowledge management, which is being recognised increasingly as critically important as organisations – private and public – attempt to operate as effectively and efficiently as possible.[1]

The published literature – the tip of the iceberg – contains a wide variety of reports, relatively few of which really address achievements in Indigenous health. A previous analysis of the literature – on cardiovascular disease among Aboriginal and Torres Strait Islander people – found that around four-fifths of the 270 articles identified focussed on disease history (including descriptive epidemiology and risk factors) (Thomson, Winter, & Pumphrey, 1999). Around one-tenth of the 270 articles reported on interventions (primary, secondary or tertiary), and the remaining one-tenth on health systems issues (such as access to services and funding issues).

Generally, of those reports that do examine programs, most describe the programs themselves – often in great detail. Some reports comment on achievements in broad terms, but very few provide real evidence. In many ways, this is not altogether surprising, as funding for many programs does not include sufficient resources to undertake rigorous evaluations. So, the published literature provides only a partial glimpse of the total 'iceberg' of achievements in Aboriginal and Torres Strait Islander health in recent years.

The importance of documenting achievements in Indigenous health, and sharing 'lessons learned' about specific interventions, is so important, however, that this report should be seen as the beginning of an ongoing process. This report benefited from limited feedback about draft versions, but widespread feedback is sought for this report. This feedback should identify omissions from the review, as well as enabling correction of any errors. It is to be hoped that publication and dissemination of the report – in hard-copy and electronic forms – will encourage people to share their experiences and achievements, and thus contribute to the ongoing efforts to improve the health of Indigenous people in Australia.

Reference

Thomson, N., Winter, J., & Pumphrey, M. (1999). *Review of the state of knowledge of cardiovascular disease among Aboriginal and Torres Strait Islander populations*. Perth: National Aboriginal and Torres Strait Islander Heath Clearinghouse

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[1] See Section 5.4 for a brief discussion of knowledge management in relation to Indigenous health.

Abbreviations

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal community-controlled Health Service; see also AMS
ACEi	Angiotensin converting enzyme inhibitor
ACR	Albumin/creatinine ratio
ACT	Australian Capital Territory
AFL	Australian Football League
AFPHM	Australasian Faculty of Public Health Medicine
AHA	Aboriginal Housing Authority
AHMAC	Australian Health Ministers' Advisory Council
AHMC	Australian Health Ministers' Conference
AHW	Aboriginal Health Worker
AIDA	Australian Indigenous Doctors' Association
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMD	Age-related macular degeneration
AMS	Aboriginal Medical Service; see also ACCHS
ANCAHRD	Australian National Council on AIDS, Hepatitis C and Related Diseases
ANU	Australian National University
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
AP Lands	Anangu Pitjantjatjara Lands
APAIS	Australian Public Affairs Information Service
ARF	Acute rheumatic fever
ARIA	Accessibility/Remoteness Index of Australia
ATSIC	Aboriginal and Torres Strait Islander Commission
BEACH	Bettering the evaluation of health care
BMI	Body mass index
CAPD	Chronic ambulatory peritoneal dialysis
CATSIN	Congress of Aboriginal and Torres Strait Islander Nurses
CDEP	Community Development Employment Projects scheme
CERA	Centre for Eye Research Australia
CGC	Commonwealth Grants Commission
CHARM	Cardiovascular health and age related maculopathy
CHD	Coronary heart disease
CIHR	Canadian Institutes of Health Research
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COAG	Council of Australian Governments
CRANA	Council of Remote Area Nurses of Australia
CRCATH	Cooperative Research Centre for Aboriginal and Tropical Health
CSDA	Commonwealth-State Disability Agreement
CVD	Cardiovascular disease
DALE	Disability Adjusted Life Expectancy
DEST	Commonwealth Department of Education, Training and Youth Affairs; formerly DETYA
DETYA	Commonwealth Department of Education, Training and Youth Affairs; now DEST – Department of Education, Training and Youth Affairs
ESRD	End-stage renal disease
FHBH	Fixing Houses for Better Health (project)

FWAHS	Far West Area Health Service of NSW
GAS	Group A streptococcus
GDM	Gestational diabetes mellitus
GP	General Practitioner
HACC	Home and Community Care
HAHU	Heads of Aboriginal Health Units (now replaced by the AHMAC Standing Committee on Aboriginal and Torres Strait Islander Health
HALT	Healthy Aboriginal Life Team
HAV	Hepatitis A
HBV	Hepatitis B
HBsAg	Hepatitis B surface antigen (a serological marker for HBV)
HCV	Hepatitis C
HECS	Higher Education Contribution Scheme
Hib	*H. influenzae* type b
HIV/AIDS	Human immunodeficiency virus/acquired immune disease syndrome
HLA	Human leucocyte antigen
ICIDH-2	WHO's International Classification of Functioning, Disability and Health
IDA	Iron deficiency anaemia
IHANT	Indigenous Housing Authority of the Northern Territory
IT	Information Technology
ITAB	Industry Training Advisory Boards
IV	Intravenous
KAMSC	Kimberley Aboriginal Medical Services Council
KM	Knowledge management
KT	Knowledge translation
LIFE	Living Is For Everyone
MAE(IE)	Masters of Applied Epidemiology in Indigenous Health
MBS	Medical Benefits Scheme
MCEETYA	Ministerial Council on Education, Employment, Training and Youth Affairs
MOU	Memorandum of Understanding
MPH	Master in Public Health
MSP	Management Support and Development Program
MSHR	Menzies School of Health Research
NACCHO	National Aboriginal Community Controlled Health Organisation
NAHS	National Aboriginal Health Strategy
NAIHO	National Aboriginal and Islander Health Organisation
NATSIS	(1994) National Aboriginal and Torres Strait Islander Survey
NCEPH	National Centre for Epidemiology and Population Health
NCVER	National Centre for Vocational Education Research
NDAC	National Disability Advisory Council
NHC	Nganampa Health Council
NHIMG	National Health Information Management Group
NHMRC	National Health and Medical Research Council
NHPA	National Health Priority Area
NHWC	National Health Workforce Committee
NPY	Ngaanyatjarra Pitjantjatjara Yankunytjatjara
NSW	New South Wales
NT	Northern Territory

NTU	Northern Territory University
NYSPS	National Youth Suicide Prevention Strategy
OATSIH	Office for Aboriginal and Torres Strait Islander Health
ORA	Outreach Australia
PBS	Pharmaceutical Benefits Scheme
PHCAP	Primary Health Care Access Program
QLD	Queensland
RACGP	Royal Australian College of General Practitioners
RAWG	NHMRC Aboriginal and Torres Strait Islander Health Research Agenda Working Group
RCIADIC	Royal Commission into Aboriginal Deaths in Custody
RHD	Rheumatic Heart Disease
RHDIP	Rheumatic Heart Disease Information Package
RHSET	Rural Health Support, Education and Training Project
RMIT	Royal Melbourne Institute of Technology
RPH	Royal Perth Hospital
RTO	Registered Training Organisations
SA	South Australia
SAR	Service Activity Reporting
SCATSIH	Standing Committee on Aboriginal and Torres Strait Islander Health: a standing committee of AHMAC
SIDS	Sudden infant death syndrome
SRDC	NHMRC Strategic Research Development Committee
STD	Sexually transmitted disease; see STI
STI	Sexually transmitted infection
SWW	Strong women workers
TAFE	Technical and Further Education
TAP	Northern Territory Tobacco Action Project
TEHO	(Aboriginal) Trainee Environmental Health Officer
TSRA	Torres Strait Regional Authority
UK	United Kingdom
UTHS	Umoona Tjutagku Health Service
USA	United States of America
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VAMHN	Victorian Aboriginal Mental Health Network
VET	Vocational Education and Training
VKHRCDU	VicHealth Koori Health Research and Community Development Unit
VSU	Volatile substance use
WA	Western Australia
WAAHIEC	Western Australian Aboriginal Health Information and Ethics Committee
WAACCHO	Western Australian Aboriginal Community Controlled Health Organisation
WHO	World Health Organization

Executive summary

The Project to which this literature review contributes

The Achievements in Aboriginal and Torres Strait Islander Health Project was commissioned from the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) by the Office for Aboriginal and Torres Strait Islander Health (OATSIH) on behalf of the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH). The aims of the project (as defined in the tender documentation) were to:

- document information about achievements in Aboriginal and Torres Strait Islander health;
- share information about achievements in Aboriginal and Torres Strait Islander health; and
- promote and build on health services, programs and strategies that have been shown to work, and other programs or strategies that have had a positive effect on the health of Aboriginal and Torres Strait Islander people.

The project, full details of which are provided in a separate volume (Shannon, Wakerman, Barnes, Hill, & Griew, 2002), consisted of three phases:

- Phase 1 – an initial literature review, parallel consultations and additional information gathering in order to provide a framework for the more detailed data collection phase.
- Phase 2 – State and Territory health authorities and non-government health services were asked to identify successful programs and provide data to the research team utilising the framework developed in Phase 1. In parallel with this data collection, the literature review was largely finalised and a draft report prepared.
- Phase 3 – this phase involved a critical analysis of the collected data examining successful programs and factors that had been identified as contributing to their success, and the production of a final project report.

The working definition of success (or achievement) used by this project, which had emerged from the project framework consultations, was:

> A success in Indigenous health is a program, project or intervention, or element thereof, that produces, or could contribute to, a demonstrated improvement in Indigenous wellbeing. This may be measured by an improvement in health outcome, other health indicators or in other process or infrastructural indicators.

The factors to be considered in assessing success, determined during the early stages of the project, were: role of the community, resourcing, sustainability, partnerships (including intersectoral collaboration), workforce issues, evaluation, accountability, and capacity building.

Methodology of the literature review

The literature review, which this volume presents, was undertaken by the Australian Indigenous Health*InfoNet* on behalf of the CRCATH. It included attention to primary, secondary and tertiary health care, as well as relevant programs in non-health sectors, such as housing and education. The review focused on achievements over the past decade.

Reflecting international and national approaches to assessing achievements in the health sector, the project took a broad, inclusive approach to the identification of achievements. Social and cultural determinants, environmental context, the provision of services, lifestyle factors, and vulnerability to specific health conditions were taken into account. Short and potential long-term achievements were considered.

In line with the initial literature review and the consultations undertaken in Phase 1 of the project, special attention was made to identify achievements demonstrating:

- an improvement to health outcomes (for example, reductions in mortality, and decreased incidence and/or prevalence of particular diseases);
- an improvement in process indicators with a proven link to better health outcomes (such as improved antenatal care leading to better obstetric outcomes; higher levels of physical

activity leading to better outcomes in terms of cardiovascular disease or diabetes; and improved awareness of particular health conditions and/or risk factors);

- an improvement in the health system or components thereof (such as health policy, data collection or the shape of service delivery, which are known to lead to improved outcomes); and/or
- improvements in other areas such as education, employment and housing (that are known to lead to improved health and wellbeing).

The process of searching for material on 'achievements' and 'success' involved a complex on-going process, as none of the main bibliographic databases (including the Australian Indigenous Health*InfoNet* bibliography) use 'achievement' or 'success' as a key word. Input from the project's phase 1 consultations highlighted specific considerations in the context of Indigenous health. This input was helpful, but, because of the difficulties associated with relevant key words, this review must be seen as a selection of achievements.

Searches were undertaken initially for international and national methods for assessing health achievements. Databases searched included Science Direct, HealthSTAR, Australian Public Affairs Information Service (APAIS), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Medline. For material specific to Indigenous health, the Australian Indigenous Health*InfoNet* bibliography[2] was the primary source of information. Searches of the databases mentioned above were used to check the completeness of this bibliography, but only a small number of new documents was identified.

A year-by-year search of the Health*InfoNet* Bibliography identified documents that could be sources of information on achievements. These documents were examined for evidence of achievements. If relevant, details were recorded in a separate EndNote library and information summarised in templates, copies of which were made available on a password-protected area of the Health*InfoNet* website for team members involved in the project.

Overview of the findings of the literature review

The literature reveals achievements in Indigenous health over the past decade across a variety of areas, including improvements in: some health outcomes; process indicators with proven links to better health outcomes; areas of the health system or components thereof; and other areas (such as education, employment and housing) that are known to lead to improved health and wellbeing.

Attempting to document achievements in Indigenous health by reviewing the literature is like trying to describe an iceberg from a glimpse of its tip, however, in that the bulk of achievements are not within view – they have never been written up for publication in the literature (even in the so-called grey literature). So, any literature review will be, by its very nature, an incomplete summary of achievements in Indigenous health.

There are three further factors pertinent to any consideration of achievements in Indigenous health. The first is the variable lead-time required between the operation of a program, project or intervention and the realisation of an outcome. For some programs, projects or interventions, the time period may be of short or medium duration. For most health conditions, however, the lead-times are long and/or uncertain. The relationship between health outcomes and 'up steam' factors (such as health policy, education or employment), while recognised, are even more complex, and the lead-times very uncertain.

Second, as well as the long (and often uncertain) lead-times between most programs, projects interventions and the achievement of positive outcomes (and even process indicators), it is important also to recognise that concerted efforts addressing the enormous health and other disadvantages experienced by Indigenous people began less than a decade ago, with Commonwealth efforts really dating only from the mid 1990s (Australian National Audit Office, 1998).

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[2] The bibliography includes details of over 6,500 items, including journal articles, books and book chapters, government and other reports, and theses.

Third, recent levels of government funding for Indigenous health have been judged by the Commonwealth Grants Commission (CGC) to be at most about half those required, with the funding of 'up-stream' areas also less than needed (Commonwealth Grants Commission, 2001).

In view of Australia's performance in health generally – and the country's wealth – the achievements in Indigenous health in the past decade, in terms of health outcomes, have been disappointing. However, given long lead-times, only recent concerted efforts, and overall under-funding, the assessment of achievements in Indigenous health is much more encouraging.

It is encouraging that governments have started to move towards the level of commitment required to achieve equitable health outcomes for Indigenous people. This move can be seen not only in the considerable increase in expenditure since the mid 1990s, which has assisted in increasing the availability of community-controlled services and in the growth and development of NACCHO and its affiliates, but also in improvements in the health infrastructure.

Examples of the improvements in the health infrastructure are the Framework Agreements, the establishment of the National Aboriginal and Torres Strait Islander Health Council, and the strengthening of inter-governmental mechanisms (with the establishment of the Standing Committee on Aboriginal and Torres Strait Islander Health, which supersedes the Heads of Aboriginal Health Units forum).

Accompanying these improvements in the health infrastructure are: improved access of Indigenous people to mainstream services (including the Medical and Pharmaceutical Benefits Schemes); growth in the Indigenous health workforce; greater availability of Indigenous health knowledge and information; and the development of a strategic research capacity in Indigenous health (particularly through establishment by the National Health and Medical Research Council (NHMRC) and OATSIH of the Aboriginal and Torres Strait Islander Health Research Agenda Working Group (RAWG) (National Health and Medical Research Council, 1998)).

There have been some improvements also in 'up-stream' factors of importance to health, such as education and housing. But, as is the case with health, the CGC recognised that much, much more needs to be done in these and other areas.

In terms of health outcomes, there appears to have been little improvement, if any, in recent years in some key health indicators (such as expectation of life and the infant mortality rate), but there is evidence of increased birth weights in response to specific programs. There is little evidence also of any real improvements in the overall levels of the major chronic health conditions (such as heart disease, cancer, diabetes and renal disease), but substantial improvements have been documented for a number of communicable diseases, at least in some parts of Australia. These include invasive pneumococcal disease and other respiratory infections, inflammatory trachoma, some sexually transmissible infections, hepatitis B virus infection, diarrhoeal disease and gastrointestinal infestations among Indigenous children, and invasive *Haemophilus influenzae* type B (Hib) disease.

In terms of process indicators with proven links to better health outcomes, there are some encouraging signs in the areas of physical activity and dietary patterns.

As well as the overall improvements in the health system summarised above, there has been substantial progress in a number of the system components. These include programs focussing on maternal and child health, initiatives in the area of substance use, the development of a variety of disease-specific programs (for renal disease, ear disorders, and skin conditions, for example), and injury prevention and control strategies.

Of the various factors identified by key informants in the consultation phase of the project, the literature review confirmed the important roles of the community (in terms both of community control and participation) and of partnerships. Resourcing was recognised as crucial at an overall level, but it was not possible to discern from the literature any clear picture of the resourcing of individual programs - except that insufficient resources have generally been allocated for evaluation. The importance of capacity building, emphasised by the National Aboriginal and Torres Strait Islander Health Council and the CGC, was clear from the literature. Encouraging developments have occurred in the Indigenous workforce, and in accountability mechanisms.

Detailed findings of the literature review

In **International and Australian health systems,** there is a growing awareness of the complex interaction of socioeconomic, cultural, environmental and personal factors (biological and behavioural) in health, and that traditional methods of assessing achievements (including traditional mortality and morbidity measures) need to be supplemented by other measures. Determinants of health, the responsiveness of health systems, and the ability of people to access services are focal points for assessment. International and national approaches combine monitoring of the efficiency of health systems with the development and use of other performance indicators.

In the **Indigenous health context**, the literature clearly demonstrated the disadvantages in health that Aboriginal and Torres Strait Islander people experience in comparison with the rest of the population. Indigenous people are exposed to many risk factors in health determinants (including physical and social environmental, genetic, biomedical, lifestyle, behavioural, attitudinal and belief factors). There are encouraging signs of the commitment of Australian governments to increasing accountability in Indigenous health and welfare. As part of this accountability, national Indigenous performance indicators have been developed and adopted by all Australian governments.

There have been improvements in factors contributing to Indigenous health. The awareness of the relationships of **education**, **employment,** and **housing and environment** to health has deepened awareness of the need for progress in these areas for Indigenous people. Methods of overcoming disadvantages in these areas have included specific targeting and the creation of pathways to facilitate access. There has been increasing participation in education and employment, and establishment of working partnerships and intersectoral links. Indigenous involvement in housing design and workforce (building and maintenance) has meant that greater attention has been directed to making housing more suited to Indigenous lifestyles and has led to skill building and improved income.

The **Indigenous health infrastructure** has been strengthened with the establishment of new bodies (for example, the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH), the National Aboriginal and Torres Strait Islander Health Council, and the Office for Aboriginal and Torres Strait Islander Health (OATSIH)) and consolidation of the role of the Indigenous community-controlled sector (the National Aboriginal Community Controlled Health Organisation (NACCHO) and State/Territory affiliates). There have been increases in funding directed to Indigenous health, and the Framework Agreements provide for more coordinated decision-making. There have been moves also to provide evidence-based direction to policies and strategies.

The literature demonstrates improvements in **access to appropriate services**. Barriers to access have been identified and methods of addressing these have been implemented. Achievements include: expansion of Indigenous community-controlled health services; greater recognition of the role of Indigenous health workers and growth in their numbers; the coordinated care trials[3]; the availability of interventions in appropriate settings; community consultation; community identification of needs; the active role of the community in their own health issues; development of partnerships and intersectoral action; adequate resourcing; culturally appropriate mainstream programs; and improved access to the Medical and Pharmaceutical Benefits Schemes.

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[3] These trials test whether multi-disciplinary care planning and service coordination lead to improved health and wellbeing for people with chronic health conditions or complex care needs.

The growing **Indigenous health workforce** is involved in various health sector areas, within mainstream and Indigenous community-controlled health services. Specific training courses have improved access for Indigenous people, and improved cultural understanding for non-Indigenous health workers. Variable progress in the various disciplines of the Indigenous health workforce – Indigenous health workers, managers, nurses, doctors and public health workers – has led to the development recently of a national strategic framework for workforce reform and consolidation.

Knowledge and information about Indigenous health has improved through: refining **health information systems;** emphasis on Indigenous-specific **research** and **ethics;** and **knowledge management.** The improved identification of Indigenous status in data collections (in censuses, and in the births and deaths registration systems and hospital utilisation collections, for example) and the increased availability of other information (such as from surveys) have assisted in the allocation of specific funding for strategies.

The establishment of the RAWG by the NHMRC and OATSIH is contributing to the development of a strategic research capacity in Indigenous health. There has been substantial growth also in the number of groups with considerable involvement in Indigenous health research, particularly Indigenous-governed research organisations.

Since the promulgation in 1991 of the NHMRC ethical guidelines, substantial progress has been made in their incorporation into the processes of institutional ethics committees across the country. Some progress has been made also in the development of guidelines for the use of health information collected as part of administrative data collections.

In terms of knowledge management for Indigenous health, there have been a number of major achievements in recent years. Not only has there been much more regular and comprehensive publication of information about Indigenous health, but also the publication of reports on specific health topics and of clinical care guidelines. A number of these reports have been disseminated also via the Internet. The Internet is also the main means of dissemination of knowledge and information by the Australian Indigenous Health*InfoNet*, which has the potential to be a key element in a national knowledge strategy for Indigenous health.

The literature details preventive strategies for Indigenous health issues. Community participation in the promotion of **physical activity** (to assist in the prevention of diabetes and cardiovascular disease, for example) has also produced social and emotional benefits for Indigenous people. Responding to community concerns about access barriers to healthy foods has improved knowledge about the role of **nutrition** in promoting health. It has resulted also in intersectoral action to increase the provision of healthy foods in remote community stores.

Addressing **alcohol abuse, cigarette smoking, illicit drug use** and **petrol inhalation** has involved multi-strategic approaches incorporating the knowledge and involvement of individuals and communities. Dealing with these issues has involved collaborative actions with initiatives from Indigenous communities (such as in education programs, lobbying actions, restrictions in access (to alcohol and petrol), patrols, and sobering up centres). Results have been demonstrated in the reduction of consumption levels, in increased awareness of 'new' issues (such as illicit drug use), and in ways to address the context of the unhealthy behaviours (such as through improved employment opportunities).

Focussing on **maternal and child health** is a vital component of Indigenous health, as many health risks can be prevented before birth, giving babies the opportunity of a good start to life. Role models have been effective for motivation and increasing access. Achievements of programs have included increases in birth weight, increased medical interaction with mothers throughout the pregnancy, and encouragement of and increase in breastfeeding.

Examples of achievements related to specific health conditions include[4]:

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[4] No attempt has been made to rank these achievements, and they are listed here in the order in which they are covered in this report.

- improved dietary patterns as a result of **nutrition** programs. Increased consumption of fruits, vegetables, wholemeal bread, fruit juices and decreased intake of sugars and carbonated soft drinks provide the foundation for reductions in obesity and diabetes;
- substantial attention has been directed to the **mental health** of Indigenous people, and the review identified a number of encouraging programs. There are limited data, however, with which to assess improvements in terms of morbidity and/or mortality;
- awareness of **cardiovascular disease**, its risk factors and issues of care is increasing among Indigenous health care workers, policy makers and Indigenous communities – it is ultimately through these efforts that significant declines in mortality and morbidity will be achieved;
- apart from pneumococcal disease, there have been reductions over the past 20 years or so in the impact of **respiratory infections** in childhood. The recent introduction of vaccination programs against pneumococcal disease offer great potential benefits for Indigenous children and at-risk adults. There is evidence of a reduction in the incidence of invasive pneumococcal disease in some parts of Australia, but, overall, it is too early for substantial achievements to have been documented. On the other hand, asthma appears to have emerged as a major problem for many Indigenous children and adults;
- substantial progress in addressing 'upstream' factors influencing the level and impact of **diabetes**. These factors include increasing attention to the disease, greater awareness and understanding among Indigenous people of the disease, its risk factors and complications, and the development of more appropriate and more accessible preventive and care services;
- development of specific programs and services – at State, regional and local level – addressing the needs of Indigenous people with **renal disease** (particularly end-stage renal disease (ESRD)); these developments have benefited from increased understanding of the epidemiology and treatment of ESRD among Indigenous people;
- greater awareness of **cervical cancer** among Indigenous women, and increased availability and uptake of appropriate screening programs;
- advances in the awareness of **breast cancer** as an issue – by Indigenous women and by Indigenous and non-Indigenous health professionals;
- some successful programs in the area of **ear disorders** have been implemented to treat existing cases of otitis media and prevent the long-term complications associated with hearing loss among Indigenous children, including collaboration between the health and education sectors; the data available suggest that the prevalence of otitis media has not been reduced over the past decade or so;
- in the area of **eye health**, the incidence and severity of trachoma has decreased generally, but inflammatory trachoma remains endemic in some remote communities of central Australia; other achievements in Indigenous eye health involve: the sharing of expertise; the employment of Indigenous health workers; the development of specialist eye health guidelines; the provision of funding and equipment to ensure better access to services (particularly in remote areas of Australia); the building of partnerships; and improvements in methodology and technology;
- reductions in the notification of some **sexually transmitted infections**, largely in response to specially developed control and prevention programs;
- implementation of appropriate strategies for **HIV/AIDS** prevention and/or management including the development of culturally appropriate resources;
- a marked reduction in the prevalence of markers of **hepatitis B** virus infection and carriage since introduction of vaccination programs (despite less than optimal responses to the vaccination among Indigenous infants);
- awareness of the emergence of **hepatitis C** virus as a significant health problem for many Indigenous people;
- reductions in rates of hospitalisation for **diarrhoeal disease and gastrointestinal infestations** among Indigenous children, largely as result of improved nutrition, better hygiene and reduced exposure to pathogenic microorganisms;

- a rapid decline in the incidence of invasive ***Haemophilus influenzae* type B** (Hib) disease in Indigenous children following the introduction of vaccination;
- development and implementation of specific guidelines for handling outbreaks of **meningococcal disease** in Indigenous communities, and enhanced surveillance for the disease;
- guidelines have been developed for community control of **scabies and skin sores**, and successful community initiated coordinated programs have occurred;
- a number of programs have resulted in reductions of certain types of **injury** among Indigenous people, but, as with many other areas, current data sources are generally inadequate for: assessment of trends; identification and quantification of most risk factors; evaluation of the efficacy and other properties of most interventions; and assessment and monitoring of the extent and distribution of these interventions;
- some recent initiatives offer promise for improvements in the **oral health** of Indigenous people, but, generally, very little attention has been directed to this important health condition;
- awareness of the needs of Indigenous people with a **disability** has increased, and attempts have been made to improve the data on needs and services. The establishment of a national Indigenous disability network should also contribute to progress in this area.

Conclusion

The literature confirms that there have been some encouraging achievements in Indigenous health over the past decade, even though improvements in health outcomes for Indigenous people have been disappointing in a country with Australia's wealth and standards of living, and performance generally in health.

In assessing achievements, allowance needs to be made for the fact that the bulk of them have never been written up for publication, the recent nature and level of government commitment, and the complex interaction between factors 'up-stream' to health, health programs, projects and interventions, and specific health outcomes.

In this context, there are clear achievements in building health infrastructure, access to appropriate health services, the Indigenous health workforce, improved knowledge about Indigenous health, and gains in specific program areas.

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1 Introduction

The literature review presented here forms part of a larger project, Achievements in Aboriginal and Torres Strait Islander Health, which was commissioned from the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) by the Office for Aboriginal and Torres Strait Islander Health (OATSIH) on behalf of the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH - a subcommittee of the Australian Health Ministers' Advisory Council) (see Appendix for details of the project).

The project aimed to document and share information about achievements in Indigenous health over the past decade, and to use this information to promote and build on the experience of health services, programs and strategies that have been shown to work. The scope of the project included primary, secondary and tertiary health care, as well as relevant programs in non-health sectors, such as housing and education. It is anticipated that the knowledge gained during the project will be used also to inform future initiatives.

The working definition of success (or achievement) used by the project (including the literature review) was:

> A success in Indigenous health is a program, project or intervention, or element thereof, that produces, or could contribute to, a demonstrated improvement in Indigenous wellbeing. This may be measured by an improvement in health outcome, other health indicators or in other process or infrastructural indicators.

The factors to be considered in assessing success were: role of the community, resourcing, sustainability, partnerships (including intersectoral collaboration), workforce issues, evaluation, accountability, and capacity building.

This report

This report summarises the key findings from the literature review, which was undertaken in two stages in conjunction with the first two phases of the project (see Appendix). The first stage focused on evidence in the literature that would inform the framework developed for the collection in phase 2 of the project of information about successful programs. The second stage of the literature review involved completion of the review and the preparation of this report. The report draws also on other aspects of the project, particularly the framework consultations, which were undertaken in phase 1 of the project.

Chapter 2 of this report outlines the methodology used for the literature review. Chapter 3 reviews international and Australian approaches to the assessment of achievements and/or performance in the health, as well as considering the assessment of achievements in Indigenous health. Chapter 4 provides a brief review of achievements in the essential 'determinants of health', and Chapter 5 summarises achievements in the Indigenous health infrastructure. Chapter 6 provides a selective overview of achievements in specific areas of Indigenous health – such as health risk factors and health conditions. Chapter 7 attempts to the place the achievements that have been made within the context of what could reasonably expected given the complex interaction between factors 'up-stream' to health, the relationship between health programs and interventions, and health outcomes, and the duration and level of government commitment.[5]

It is important to realise that this report is a summary of the literature identified, rather than an inclusive overview of all the literature. Attempts were made to locate and collect all of the literature, but, an unknown amount of the grey literature will not have been identified because it is not included generally in the main indexes. Further, not all of the literature identified have been included in this report. As noted below, around 1,600 items were identified as

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[5] The consideration of how achievements measure up to what could be expected is a major undertaking in itself - of the type undertaken by the Australian National Audit Office or the Commonwealth Grants Commission.

possibly relevant to this project. The compilation of this report involved some selection from those articles deemed to have some relevance to achievements in Indigenous health. Every effort was made to ensure that this selection included good examples of achievements, but it is probable that some examples may have been excluded.

For consistency in presentation, most health areas (be they health risk factors or health conditions) have been covered in the same order throughout this report. As with any ordering, it is somewhat arbitrary, but this appeared preferable to varying the order of presentation.

Reference

Australian Bureau of Statistics, & Australian Institute of Health and Welfare. (2001). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2001* (ABS Catalogue No.4704.0, AIHW Catalogue No. IHW 6). Canberra: A joint program of the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

2 Methodology

The literature review was undertaken by a small team at the Australian Indigenous Health*InfoNet* over the period October 2001-April 2002. As determined by the project guidelines, the review was limited largely to references published since 1992.

Reflecting recent international approaches to assessing achievements in the health sector – and current 'definitions' of Aboriginal and Torres Strait Islander health (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001) – this project took a broad, inclusive approach to the identification of achievements. Social and cultural determinants, environmental context, the provision of services, lifestyle factors, and vulnerability to specific health conditions were taken into account. Short and potential long-term achievements were considered. Literature was selected according to indications of improvement for Aboriginal and Torres Strait Islander health. Examples of interventions demonstrating generally acceptable measures of success – such as decreased incidence and/or prevalence of disease, improvements in health trends, the identification and reduction of risk factors and the improvement of social determinants of health – were included.

The process of searching for material on 'achievements' and 'success' involved a complex on-going process, as none of the main bibliographic databases (including the Australian Indigenous Health*InfoNet* bibliography) use 'achievement' or 'success' as a key word. A number of key words may be relevant – 'health outcomes' and 'best practice' are examples – but generally the identification of appropriate material was not straightforward. Brainstorming among team members at the Australian Indigenous Health*InfoNet* and contact with other project team members (during telephone conversations, in teleconferences and by email) crystallised ideas about elements of success. Input from the project's phase 1 consultations highlighted specific considerations in the context of Indigenous health, which are described later in this report. All of these aspects were helpful, but, because of the difficulties associated with relevant key words, this review must be seen as a selection of achievements.

Searches were undertaken initially for international (mainly UK, USA, Canada) and national methods for assessing health achievements. Sources were documents held at Edith Cowan University and those found on the Internet, including database searches. Databases searched included Science Direct, HealthSTAR, Australian Public Affairs Information Service (APAIS), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Medline.

For achievements in Indigenous health, and information on the context of those achievements, the Australian Indigenous Health*InfoNet* bibliography[6] was the primary source of information. The bibliography includes details of over 6,500 items, including journal articles, books and book chapters, government and other reports, and theses. Searches of Science Direct, HealthSTAR, APAIS, CINAHL and Medline were used to check the completeness of the Australian Indigenous Health*InfoNet* bibliography, but only several new documents were identified.

A year-by-year search of the Australian Indigenous Health*InfoNet* Bibliography identified documents that could be sources of information on achievements. These documents were examined for evidence of achievements and, if relevant, details were recorded in a separate EndNote library and information summarised in templates. The summaries were compiled from the source documents and, if necessary, additional documents were referred to.

The separate bibliography and copies of the templates were made available on a password-protected area of the Australian Indigenous Health*InfoNet* website for team members involved in the project.

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[6] The EndNote version of the bibliography used by the Health*InfoNet* is a little different to the version available on-line through the Internet (http://www.healthinfonet.ecu.edu.au/).

3 Assessing achievements

3.1 International approaches to achievements in the health sector

Assessment of achievements in the health sector has long relied on specific health indicators. These have included various mortality and morbidity measures (for example, death rates, expectation of life at birth and the incidence of specific diseases, such as cancers), and the prevalence of health-related behaviours (for example, cigarette smoking, alcohol consumption and physical activity). Reliance on such indicators is not adequate, however, largely because health depends on a complex interaction of socioeconomic, cultural, environmental and personal factors (biological and behavioural), and the nature and availability of health services (Australian Institute of Health and Welfare, 2000; World Health Organization, 2000). Reflecting this inadequacy, and also to monitor progress towards specific health goals, a number of countries have directed increasing attention in recent years to assessing the performance of the health system.

More generally, the World Health Organization (WHO) has been developing a framework for assessing the attainment and performance[7] of health systems in a consistent manner internationally (Murray & Frenk, 2000; World Health Organization, 2000). According to the WHO, health systems have a responsibility to their country's citizens 'not just to improve health but to protect them against the financial cost of illness – and to treat them with dignity' (World Health Organization, 2000, p.8). The WHO framework comprises three broad categories: health, responsiveness, and fairness in financial contribution. As its health measure, the WHO framework uses the derived indicator, Disability Adjusted Life Expectancy[8] (DALE), both overall and in its distribution within the population.

Responsiveness is a measure of 'how the system performs relative to non-health aspects, meeting or not meeting a population's expectations of how it should be treated by providers of prevention, care or non-personal services' (World Health Organization, 2000, p.31). The concept includes attention to respect for persons (including dignity, confidentiality and autonomy of individuals and families to decide about their own health) and client orientation (including prompt attention, access to social support networks during care, quality of basic amenities, and choice of provider). Like the health measure, WHO provides for an overall measure of responsiveness and one that captures its distribution within the population.

For a health financing system to be fair, it needs to ensure that 'households should not become impoverished, or pay an excessive share of their income in obtaining needed health care' and 'poor households should pay less towards the health system than rich households' (Murray & Frenk, 2000, p.720).

In its first application of this framework, Australia ranked 12th out of the 191 WHO Member States for overall goal attainment, but only 32nd for overall health system performance. For goal attainment, Australia ranked second for DALE, but only 17th when distribution was taken into account. Aggregating these health measures with those for responsiveness and fairness in financial contribution, Australia had a ranking of 12th for goal attainment. In terms of performance, which takes account of resources available, Australia slipped to 39th on level of health and 32nd in overall health system performance.

In contrast to WHO's overall approach, individual countries have generally focused more closely on specific measures of health (and, increasingly, on factors contributing to health).

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[7] Attainment is the actual achievement of the health system, while performance is a measure of this achievement related to the individual country's resources.

[8] Disability Adjusted Life Expectancy (DALE) is, as the name suggests, a measure adjusting expectation of life with years lived with a disability. DALE is estimated from three kinds of information: the fraction of the population surviving to each age, calculated from birth and death rates; the prevalence of each type of disability at each age; and the weight assigned to each type of disability, which may or may not vary with age.

The United States is probably the country with the longest history of attempting to assess performance of the health system, at least in relation to health goals and targets, and it has recently finalised leading health indicators for Healthy People 2010 (the third generation of its decade-long goals and targets process) (Chrvala & Bulger, 1999). The leading indicators have been grouped, with some repetition, into the following three sets:

- health determinants and health outcomes – comprises specific indicators of the physical environment, poverty, education, tobacco use, weight, physical activity, health insurance, early detection of cancer, preventable deaths from injury, and disability;
- life course determinants – tobacco use, health care access, low birth weight, physical activity, poverty, cognitive development, substance abuse, violence, and disability; and
- prevention-oriented – disability, preventable deaths from injury, poverty, tobacco use, childhood immunisations, cancer screening, hypertension screening, diabetes management, and health care access.

Canada has taken a more inclusive approach to health indicators, which have been grouped in the following categories (Statistics Canada and Canadian Institute of Health Information, 2001):

- health status – comprising measures of wellbeing, health conditions, human function and death;
- non-medical determinants of health – health behaviours, living and working conditions, personal resources, and environmental factors;
- health system performance – acceptability, accessibility, appropriateness, competence, continuity, effectiveness, efficiency, and safety; and
- community and health systems characteristics – populations and sub-populations, expenditures and health workforce, etc.

A similar approach, including attention to the various determinants of health, has been followed by the UK Department of Health for measuring progress towards a number of national health targets (Statistics Division and Central Health Monitoring Unit. Department of Health (UK), 2001). The targets have been set largely using traditional indicators (such as level of reduction in mortality in a time period). In recognition of the fact that the time frame for many of these measures can be quite long, progress in the shorter term will be assessed by a broad range of measures, including 'upstream' fundamental factors 'closer to the point of causation' (for example, access to affordable nutritious foods, etc.) and lifestyle determinants.

The nature of the measures used to monitor progress will depend, to some degree, on the scope and focus of the health strategy. To cope with a full range of strategies, including those tackling the fundamental social determinants of health, the UK document categorises measures of progress into four broad groups:

- lifestyle – aspects relating to health-related behaviours (for example, cigarette smoking, alcohol consumption and physical activity);
- environment – external aspects impacting on health (such as environmental contamination, housing and associated infrastructure, transport, etc.);
- services – availability [and accessibility] of appropriate services (for example, cancer-screening programs, pharmaceutical services, and tertiary-level services); and
- social and economic – broad social indicators (such as personal and community control and empowerment, education, employment, income).

At much the same time, the WHO, in releasing its *International Classification of Functioning, Disability and Health*, has extended key health indicators to include aspects relating to functioning and disability (World Health Organization, 2001). This shifts the focus from mortality and morbidity to 'life' (that is, how people live with their health conditions and how these can be improved to achieve productive, fulfilling lives).

3.2 Indicators for performance of the Australian health system

In parallel with these developments internationally, the Australian Health Ministers' Conference established an Australian National Health Performance Committee to develop a measurement framework for the health system (National Health Performance Committee, 2001).[9]

The Committee has built on previous work by the Australian Institute of Health and Welfare (Australian Institute of Health and Welfare, 1999) and the National Public Health Partnership (National Public Health Partnership, 2000) in developing a three tier framework (National Health Performance Committee, 2001), the three tiers and example indicators being:

- health status and outcomes – direct measures of health and wellbeing, such as indicators of morbidity and mortality. These include incidence and prevalence of specific disorders, injury or other health-related states; standardised and age and/or sex and/or condition specific death rates; expectation of life; alterations to body structure or function (impairment), activities (activity limitation) and participation (restrictions in participation). Also included are broad measures of physical, mental, and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).
- determinants of health – factors that have either a positive or negative influence on health at the individual or population level. These include: patterns of tobacco use; percentage of people achieving 'sufficient' physical activity; percentage of people overweight or obese; unemployment and participation in the labour force; and environmental tobacco smoke.
- health system performance – indicators for a range of service categories and types of interventions across the spectrum of the health care system. This includes population health programs, primary care services, and the acute and continuing care sectors. The types of indicators relate to the specific area within the health system. Population health indicators include: percentage of women aged 50-69 years who are screened for breast cancer; and percentage of children fully vaccinated at 12 months of age. Primary care indicators include: number of general practitioner services per patient per region per year; and rate of general practitioner antibiotic prescribing for presentations of upper respiratory tract infection. Acute care indicators include: hospital separation rates per 1,000 population; emergency department waiting times; cost per casemix-adjusted separation; and average length of stay. Continuing care indicators include: separations from hospitals to aged care homes for patients over 70 years; and ratio of Home and Community Care (HACC) hours of service provision.

Overall it is recommended that generic indicators should have the following qualities:

- be worth measuring;
- be measurable for diverse populations;
- be understood by people who need to act;
- galvanise action;
- be relevant of policy and practice; and
- measurement over time will reflect results of actions (National Health Performance Committee, 2001).

3.3 Other factors in the consideration of health outcomes

Another aspect that should be borne in mind in considering the achievement in specific health outcomes is the variable lead-time required between the operation of a program, project or intervention and the realisation of some outcome. For some programs, projects or interventions the lead-time is short. An example is the response of an individual patient to some proven therapy (such as an appropriate antibiotic for a bacterial infection). For other

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[9] The development of specific performance indicators for Indigenous health is summarised in Section 3.4.

programs, projects or interventions, the lead-time may be of medium duration, such as the reduction in the incidence a particular disease in response to the introduction of a vaccine (the vaccine for *Haemophilus influenzae* type B is an example).

For many programs, projects or interventions, however, the lead-times are long and/or uncertain. This is particularly so for major health programs, and for interventions for health conditions where a person's health risks, knowledge, attitudes, opportunities, behaviour and access to services have a great bearing on outcomes. These latter aspects, which have important implications for what can be expected in terms of health outcomes, involve:

- varying exposure of individuals to risks;
- understanding and attitudes in relation to prevention, ill health and its treatment;
- willingness and ability of people to look after their own health, and to seek and follow professional help when needed; and
- access to quality professional help (Australian Institute of Health and Welfare, 2000)

The application of these aspects to conditions like diabetes, heart disease and cervical cancer, for example, illustrate the potential barriers to achieving measurable health outcomes within a short timeframe (such as a few years). Generally, the most that can be expected within a short timeframe is an improvement in some process indicator linked to the health outcome of interest (for example, dietary changes aiming at weight reduction for diabetics). But, of course, such process indicators may not be even monitored systematically at population level, let alone reported in the literature. For some conditions, such as lung cancer and mesothelioma, the elapsed time between exposure and disease is very long – in the order of 20 years (any intervention needs to recognise this long latent period).

The relationship between health outcomes and aspects like health policy, education or employment, while recognised, are even more complex, and the lead-times very uncertain.

In summary, the often long and uncertain lead-times between the operation of programs, projects or interventions and the achievement of positive outcomes need to be borne in mind when considering the achievements identified by this review.

3.4 Assessing achievements in Indigenous health

The context of Indigenous health

The burden of ill-health

According to available data, over the last 20 to 30 years there have been some health gains for Indigenous people (such as reductions in child mortality, and in the prevalence in communicable diseases) (National Aboriginal and Torres Strait Islander Health Council, 2000). However, Indigenous people generally suffer a greater burden of ill health than the general population. Over the period 1997-1999, the life expectancy at birth for an Indigenous male was 56 years and for an Indigenous female, 63 years. In the total Australian population today, males have a life expectancy of 76 years and females 82 years (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

The leading causes of death – for both the Indigenous and non-Indigenous populations – were diseases of the circulatory system (including heart attacks and stroke), injuries (including motor vehicle accidents, assaults and homicide, and self-inflicted injury), and cancer (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). These diseases accounted for 60% of all identified Indigenous deaths and affected Indigenous people at younger ages than in the total Australian population. There were 7-9 times more deaths of Indigenous people from endocrine and metabolic diseases (particularly those related to diabetes) than expected from rates for the total population.

Information about the burden of specific diseases and conditions is presented later in this report in conjunction with the consideration of achievements in these areas.

Factors contributing to the burden of ill-health among Indigenous people

As noted above, health is determined by many factors: environmental; genetic; biomedical; lifestyle and behaviour and attitudes and beliefs – these can either act alone or in conjunction with others (Australian Institute of Health and Welfare, 2000). Some differences in health status can be explained by differences in the health risk factors to which Indigenous people are exposed. Indigenous people, as a group, are more likely than other Australians to be exposed to low socioeconomic status, poor living conditions, poor nutrition, the use of harmful substances, and violence.

Social disadvantage, in particular, places Indigenous people at a greater risk of ill health. The Social Health Atlas of Australia notes the disparities in health that exist between groups in the population (Glover, Harris, & Tennant, 1999). People of low socioeconomic status experience worse health than those of higher socioeconomic status for almost every major cause of mortality and morbidity. There are indications that health risk behaviours (such as smoking and excessive alcohol consumption) are more likely to occur among socially disadvantaged groups (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

Underlying Indigenous social – and health – disadvantages are aspects of Indigenous history including: overt and covert discrimination; isolation; powerlessness; loss of land; forced dependence; poverty; and childhood separations (Swan & Raphael, 1995). These factors are seen as contributing to the violence in Indigenous communities, and the interrelationships between mental health and domestic violence, child abuse and neglect (including sexual abuse), alcohol and other substance abuse. Rates of intentional injury, either self-inflicted or caused by assault, may be an indicator of psychological illness and distress in the community (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

Addressing the burden of ill-health among Indigenous people

Consideration of achievements in Indigenous health needs to recognise that concerted efforts addressing the burden of ill-health are relatively recent (Australian National Audit Office, 1998), and that 'overall funding ….. is significantly below what would be expected for a group with such a poor health status' (Commonwealth Grants Commission, 2001, p.5).

The first real attempt by governments to address Indigenous health issues occurred in 1968, the year following the referendum which gave the Commonwealth Government power to legislate for Indigenous people, and allowed for their inclusion in the census (Australian Indigenous Health*InfoNet*, 2001; Australian National Audit Office, 1998). The newly established Office of Aboriginal Affairs identified health as one of four major areas for Indigenous development, and initiated specific purpose grants to the States for the development of special Indigenous health programs. State government health authorities decided to establish Indigenous health units to address the health needs of Indigenous people and to administer the Commonwealth funds.

It is also around thirty years since the first Indigenous controlled health service was established in Redfern (Sydney) in 1971 (Australian Indigenous Health*InfoNet*, 2001).

Some years after the establishment of the Office of Aboriginal Affairs,[10] and of the State-based Indigenous health units, a 1979 Australian Parliamentary report noted 'the failure of health authorities to give sufficient attention to the special health needs of Aboriginals', and concluded that 'if the Commonwealth and State Governments … had accepted their full responsibilities the disastrous Aboriginal health situation would not exist' (House of Representatives Standing Committee on Aboriginal Affairs, 1979, p.iii).

This report resulted in some increase in government efforts, but it was 1987 before a combined meeting of Commonwealth, State and Territory ministers for health and Indigenous affairs agreed to develop a national Aboriginal health strategy (Australian National Audit Office, 1998). Even though this strategy (which had been endorsed by ministers in 1990) was never effectively implemented (Australian National Audit Office, 1998; National Aboriginal Health Strategy Evaluation Committee & Gordon, 1994), the work of National Aboriginal Health Strategy Working Party did result in increased attention being directed to Indigenous health in the early 1990s.

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[10] The Office of Aboriginal Affairs became the Department of Aboriginal Affairs in 1972.

It was not until the mid 1990s, however, before government commitment to Indigenous health started to approach that required for the persisting health disadvantages experienced by Indigenous people. A key aspect of this increased commitment was the decision by Australian health ministers in June 1995 to develop Framework Agreements involving Commonwealth, State/Territory governments and the Indigenous controlled sector. This decision was accompanied by a substantial increase in Commonwealth allocations and the transfer of responsibility for Indigenous health at the Commonwealth level from the Aboriginal and Torres Strait Islander Commission (ATSIC) to the then Department of Human Services and Health (Australian National Audit Office, 1998). The increase in Commonwealth allocations assisted the consolidation and expansion of the role of the Indigenous community-controlled sector.

As noted by the Commonwealth Grants Commission (CGC) in 2001, however, actual level of resources allocated to Indigenous health was 'significantly below what would be expected for a group with such a poor health status' (Commonwealth Grants Commission, 2001, p.5).

Estimated total expenditure by Australian governments and the private sector on health services to Indigenous people in the 1998-1999 financial year was $1,245 million (Australian Institute of Health and Welfare, 2001). This is equivalent to $3,065 per person compared with $2,518 per person for non-Indigenous people - a ratio of 1.22:1 (this compares with a ratio of 1.08 in 1995-96 (Deeble et al., 1998)). When relative income position is taken into account, public expenditure on the health of Indigenous people appeared to be similar to that for non-Indigenous people in low-income groups, despite the much lower health status of Indigenous people (Australian Institute of Health and Welfare, 2001).

The majority of Indigenous health expenditure was allocated through mainstream health programs which generally do not, or only incompletely, document use specifically by Indigenous people (Australian Institute of Health and Welfare, 2001). Medicare data, for example, do not include an Indigenous identifier.

Indigenous people were, on average, much higher users than non-Indigenous people of publicly funded health services and State-funded health services, particularly admitted patient services in hospitals and community health services (Australian Institute of Health and Welfare, 2001). Compared with non-Indigenous people, Indigenous people used fewer private services such as doctors in private practice, private hospitals, dentists and privately funded allied health professionals.

The Commonwealth and State governments contributed very similar amounts to health services for Indigenous people (Australian Institute of Health and Welfare, 2001). Over 50% of the Commonwealth's contribution was indirect through its contribution to public hospital funding. Expenditures were much lower for Indigenous people than for other Australians in the major Commonwealth-funded health programs, Medicare and the Pharmaceutical Benefits Scheme. Per person expenditure on Indigenous people was 37% of that for non-Indigenous people.

The ratio of Indigenous to non-Indigenous service use would be lower than the expenditure ratio of 1.22:1 if the higher costs of providing service in remote areas could be factored in (Australian Institute of Health and Welfare, 2001). Access to Medicare funded services and pharmaceutical benefits decreased as remoteness increased, but admitted patient expenditure increased with increasing remoteness.

After considering the overall health burden experienced by Indigenous people, current level of resources devoted to Indigenous health, and the views of a number of experts and groups, the CGC concluded that 'the poorer health status of Indigenous people, and their greater reliance on the public health [care] system, would justify at least a doubling of the average per capita expenditure on non-Indigenous people (Commonwealth Grants Commission, 2001, p.127).

The CGC conclusion about the inadequacy of spending on health services was matched with similar conclusions about expenditure in a number of health-related areas – such as education, training, employment, housing and infrastructure (Commonwealth Grants Commission, 2001). In view of the importance to health of these 'up-stream' factors, the achievement of major gains in Indigenous health will require a much greater commitment by governments than simply a two-fold increase in spending on health services.

In summary, concerted government efforts addressing Indigenous health disadvantages are relatively recent, with Commonwealth efforts really dating only from the mid 1990s.[11] Recent levels of government funding for Indigenous health have been judged by the CGC to be only about half those required, with the funding of 'up-stream' areas also less than needed. These factors, combined with the often long and uncertain lead-times between the operation of programs, projects and interventions and the realisation of positive health outcomes, mean that it is unrealistic to expect that substantial gains in health status of Indigenous people will have been achieved in the relatively recent time period since government efforts started to move towards the levels required.

Accountability in Indigenous health

Australian governments are increasingly committed to accountability in Indigenous health and welfare (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). There is a need for monitoring the effectiveness of programs and the evaluation of policies that are designed to improve the status of and service delivery to Aboriginal and Torres Strait Islander people. There is an emphasis on evidence-based approaches to policy and program development, growing demand for high quality Indigenous information and data at a range of geographic levels for the development of performance indicators on service delivery, and for the provision of time series on health status and social conditions.

According to the National Aboriginal and Torres Strait Islander Health Council, investing in Aboriginal and Torres Strait Islander health must lead to real and sustained long-term improvements in health outcomes which can be demonstrated, firstly to Aboriginal and Torres Strait Islander communities and secondly to investors (National Aboriginal and Torres Strait Islander Health Council, 2000). Decisions should be based on priorities developed jointly between Commonwealth, State, Territory and local governments, the Aboriginal and Torres Strait Islander Commission (ATSIC) and Aboriginal and Torres Strait Islander communities. Resources should be allocated according to need, real costs of delivery, and capacity to deliver health outcomes. There is a need for the efficient and effective use of public monies and business plans, and outcomes data need to be documented and made public for accountability.

The Aboriginal and Torres Strait Islander Commission Act 1989 gives ATSIC broad powers to monitor the effectiveness of programs for Aboriginal and Torres Strait Islander people, including programs developed by other Commonwealth Government agencies (Commonwealth Department of Health and Aged Care, 2001). Partnerships between different spheres of government, the community sector and ATSIC are regarded as the key to achieving improved access and improved health status (Commonwealth Grants Commission, 2001).

Performance indicators

Government approaches to assessing achievements in Indigenous health have occurred for many years, but, until recent years, they have been somewhat piecemeal. In 1997, Australia's health ministers agreed to a set of interim performance indicators against which all jurisdictions were to report in 1998 (National Health Information Management Group NHIMG, 2000). The development of the indicators was a cooperative effort involving the National Aboriginal Community Controlled Health Organisation (NACCHO), the Australian Institute of Health and Welfare (AIHW), the Australian Bureau of Statistics (ABS), the Heads of Aboriginal Health Units (HAHU) from the Commonwealth, State and Territory health authorities, and a number of other people with expertise in Indigenous health information. The set of 56 indicators grouped into nine categories produced by this effort was advanced, its

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[11] It is possible that increased efforts in some States may have commenced from the early 1990s.

inclusion of measures relating to aspects such as community involvement and intersectoral issues pre-dating their inclusion in other sets of indicators. The nine categories were:

- Life expectancy and mortality;
- Morbidity;
- Access;
- Health service impacts;
- Workforce;
- Risk factors;
- Intersectoral issues;
- Community involvement; and
- Quality of service provision.

As noted above, this was always seen as an interim set of indicators. Also, the compilation by jurisdictions of their reports against this interim set identified a number of difficulties and requirements, including:

- the relatively poor quality and/or availability of data for some indicators;
- uncertainty about population estimates;
- uncertainty about the agency responsible for reporting of particular indicators;
- the complexity of some indicators, and the need for technical refinement;
- the need for indicators addressing emotional and social wellbeing;
- the lack of clear guidelines for interpretation and reporting; and
- the need for targets for each indicator (the lack of accurate baseline data is a major problem) (National Health Information Management Group NHIMG, 2000).

In 2000, the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) was commissioned by the AIHW to undertake a refinement of this set (Cooperative Research Centre for Aboriginal & Tropical Health, 2000). This thorough Australia-wide process, involving extensive consultation, resulted in the adoption by AHMAC of a set of 56 indicators (including some relating to emotional and social wellbeing) (Office for Aboriginal and Torres Strait Islander Health, 2000b), grouped according to whether they were primarily related to:

- government inputs;
- social equity;
- access to health services;
- risk markers; or
- outcomes for people.

To assist jurisdictions in reporting against this revised set of performance indicators, detailed technical specifications were compiled (Office for Aboriginal and Torres Strait Islander Health, 2000b). It is anticipated that ongoing developments – both in Aboriginal and Torres Strait Islander health and in the area of performance indicators – will necessitate further refinement of the current set of performance indicators for Aboriginal and Torres Strait Islander health (Cooperative Research Centre for Aboriginal & Tropical Health, 2000). It is planned that Commonwealth, State and Territory health authorities, in conjunction with the ABS and the AIHW will report annually on these national performance indicators and targets (Commonwealth Department of Health and Aged Care, 2001).

Periodic assessment of performance against an agreed set of indicators is one way that achievements in Indigenous health can be measured, and should be. However, many grass-roots achievements may not be reflected in these indicators, and there is a need for a more inclusive approach to documenting – and sharing – achievements in Indigenous health. This is important for two reasons. First, focussing on national performance indicators may miss some important local achievements, thus providing an incomplete picture. Second, it is important that information about grass-roots achievements is shared, so that others can learn from these achievements, and replicate the programs (if appropriate).

Examining success or achievement in Indigenous health

The working definition of success (or achievement) for this project, which emerged from the project framework consultations (see Shannon, Wakerman, Barnes, Hill, & Griew, 2002), is:

> A success in Indigenous health is a program, project or intervention, or element thereof, that produces, or could contribute to, a demonstrated improvement in Indigenous wellbeing. This may be measured by an improvement in health outcome, other health indicators or in other process or infrastructural indicators.

Four areas emerged from an initial review of the literature and framework consultations as means by which to identify an achievement:

- An improvement to health outcomes, for example an improved infant mortality rate or reduced prevalence of disease in a community.
- An improvement to process indicators with a proven link to better health outcomes, such as improved antenatal care (leading to better obstetric outcomes); higher levels of physical activity (leading to better outcomes in terms of cardiovascular disease or diabetes).
- An improvement in the health system or components thereof, such as health policy, data collection or the shape of service delivery, which are known to lead to improved outcomes.
- Improvements in other areas such as education, employment and housing that are known to lead to improved health and wellbeing.

These areas of achievement are consistent with those identified in the National Performance Indicators for Aboriginal and Torres Strait Islander Health (Office for Aboriginal and Torres Strait Islander Health, 2000a).

Key informants to the project's framework consultations identified a number of factors as important contributors, or potential contributors, to success. Brief summaries of each of these factors – or contributors to success – are documented below.

Role of the community

The role of the community was seen as a crucial aspect. This ranged from the community-control of primary health care services to more general community participation and involvement in health and other matters. Factors seen as important were:

- community participation should exist at all levels, including management;
- community involvement should be actual and not symbolic;
- when considering issues of community control, government and other mainstream services should not be excluded;
- consideration needs to be given to what constitutes appropriate community representation and Indigenous ownership;
- community control of research processes (including ethical assessment and oversight) and outcomes;
- community perceptions and values are often not reflected in the priorities of government and other funding bodies;
- the enhancement of community capacity is critical, in a broad sense that includes all aspects of community wellbeing.

Resourcing

Key informants, who noted that one of the main aims of the Australian health care system is to achieve equity for all Australians, saw adequate resourcing of projects, programs and interventions as important also. The common definition of equity – 'equal access to health care for equal need' (McDermott & Beaver, 1996, p.13) – raises questions as to how 'need' and 'access' are defined and how they are measured.

Attention was drawn to the report of the CGC of inquiry into Indigenous funding (Commonwealth Grants Commission, 2001), which acknowledged that reliable data on need are not generally available because:

- measures may not assist with resource allocation decisions (for example, hospital separation data reflect met need and not the extent to which there are unmet needs and gaps in service delivery);
- it is difficult in some cases to identify funds used to meet Indigenous needs, especially within mainstream programs;
- needs may not be met because of systemic or other structural problems; and
- broad measures mask variations at the local level.

Key informants commented also on the CGC finding that the poor health status of Indigenous people would justify at least a doubling of current expenditure (see above) (Commonwealth Grants Commission, 2001). Key informants noted also that the Deeble report (Deeble et al., 1998), the first real attempt to assess the actual level of expenditure on Indigenous health, had a deep effect on Commonwealth policy and resulted in a number of initiatives to reform the Australian financing system in Indigenous health (Australian Institute of Health and Welfare, 2001).

Generally, the framework consultations suggested the following issues be considered:

- whether funding was sufficient to meet the needs and objectives of the program, project or intervention – adequacy of resources;
- projects are often 'set up to fail' when they don't have/receive adequate funding; and
- whether programs, projects or interventions represented value for money.

Sustainability

Appropriate resourcing was seen as one important aspect in the sustainability of programs, projects and interventions. Key informants noted the problems associated with the short-term commitment of funds to projects. These problems included the inability to plan ahead, high staff turnover, and general uncertainty. There was a need also to review funding levels periodically, to ensure they were adequate and had the capacity to respond to emerging and changing needs within communities. Informants commented on the problems with one-off, demonstration or pilot projects, unless there was a longer-term commitment to ongoing funding, if successful, and wider uptake of models developed through such projects.

The interviews noted examples in which improved health outcomes had been demonstrated, but the improvement had not been sustained. Failure to sustain improvements may simply be the result of loss of special funding. However, funding alone should not be seen as the key to sustainability. Other factors – such as the changes in specific staff involved, a failure to sustain behavioural changes, or a change in community priorities (because of the perception that a particular issue is no longer a problem in the community) – can be equally important.

Partnerships, including intersectoral collaboration

In commenting on the importance of partnerships, key informants noted that the CGC inquiry into Indigenous funding concluded: 'the importance of effective agreements and partnerships between levels of government and Indigenous communities, both within the health sector and in other areas, cannot be overstated' (Commonwealth Grants Commission, 2000). This sentiment is very similar to the importance attached to partnerships and intersectoral collaboration in the1989 National Aboriginal Health Strategy (National Aboriginal Health Strategy Working Party, 1989).

Formal partnerships include the joint planning forums established in each jurisdiction from the Framework Agreements on Aboriginal and Torres Strait Islander Health (Australian National Audit Office, 1998). These forums include Commonwealth and State/Territory governments, Indigenous community-controlled health organisations and ATSIC. The Primary Health Care Access Program (PHCAP) aims to assist in improving comprehensive primary health care provision in areas where needs have been identified through joint regional planning. Within the research area, key informants noted that there were increasing numbers of collaborations between Indigenous communities and research agencies. Examples include the Cooperative Research Centre for Aboriginal and Tropical Health, the VicHealth Koori Health Research and Community Development Unit, the University of Queensland's Indigenous Health Program and the TVW-Telethon Institute of Child Health Research.

Key informants noted that it is important also to consider informal partnerships at the local community level, which demonstrate a genuine commitment by a number of sectors to working together to address community-identified priorities.

The following issues were raised also during the consultations:

- the need for partnerships between all those active at a community level (paid, unpaid, government and non-government);
- a broad range of strategies is needed (for example, in addressing alcohol problems, there is a need for strong links between night patrols, sobering-up shelters, counselling facilities and treatment centres);
- there are examples of Indigenous community controlled health services advocating for intersectoral collaboration, such as in the area of housing; and
- despite agreement about the importance of intersectoral collaboration, there is a paucity of documented examples of successful collaborations.

Workforce issues

Key informants noted that a number of significant developments in the Indigenous health workforce have occurred over the past decade, but there is continuing Indigenous under-representation in the medical, nursing and allied health workforce. Significant changes have occurred in the training of Indigenous doctors. For example, the University of Newcastle's problem-based learning curriculum, specific support structures for Indigenous students and community-oriented recruitment processes have given it substantial success in graduating Indigenous doctors.

The important role of Indigenous health workers in the delivery of services to communities was noted. However, respondents reported substantial differences across States and Territories in relation to the roles of health workers, educational standards, and recognition within a career structure. These issues are recognised in the Draft National Strategic Framework for the Aboriginal and Torres Strait Islander Workforce (Office for Aboriginal and Torres Strait Islander Health, 2001a).

Key informants pointed out that the Master of Applied Epidemiology (Indigenous Health) program at the Australian National University was providing opportunities for public health and research training for Indigenous people. It was acknowledged that an increasing number of Indigenous people were involved in research, but key informants commented that there was need for more widespread training for Indigenous researchers.

Interest from Indigenous doctors in Master of Public Health (MPH) courses and in advanced public health training through the Australasian Faculty of Public Health Medicine (AFPHM) have created career paths for Indigenous doctors interested in public health.

Career pathways for other disciplines, particularly nursing, were being developed through the Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN), the Council of Remote Area Nurses of Australia (CRANA) and the network of University departments of rural and remote health.

During the consultations, it was evident that workforce issues will play an important role in understanding the contributors to success in relation to specific projects. There have been numerous reviews and reports on workforce issues in relation to Aboriginal and Torres Strait Islander health, but there is no detailed analysis of the workplace issues and the underlying reasons why, in particular instances, the success of a project or program may be attributed to the workforce.

Specific issues raised during the consultations included the following:

- management practices and the need for management training;
- personal skills as well as specialised health worker skills required;

- the need for clear descriptions and objectives for staff positions;
- staff support issues, particularly in relation to recognition of skills and ongoing professional development needs;
- management skills needed to liaise with a wide range of stakeholders in Indigenous health; and
- the need to train and develop the skills of Indigenous researchers.

Evaluation

A number of key informants expressed the view that evaluation of programs and interventions in Aboriginal and Torres Strait Islander health is only just beginning to take place, and there is a general lack of information on what works and what doesn't. The health sector overall, however, has been moving towards an evidence-based approach that informs decisions about policy direction and the targeting of resources. Systematic reviews of the evidence base for clinical and public health practice are being used for the development of clinical care guidelines and intervention programs for conditions such as type 2 diabetes (Couzos, Metcalf, Murray, & O'Rourke, 1998), otitis media (Couzos, Metcalf, & Murray, 2001; Menzies School of Health Research, 2001) and eye health (Office for Aboriginal and Torres Strait Islander Health, 2001b).

In terms of the evaluation of specific programs, projects or interventions, the following issues were raised during the consultations:

- an evaluation strategy should be a requirement of program or service planning;
- adequate resources should be allocated as part of the budget;
- performance criteria need to be appropriate and achievable so the project is not 'set up' to fail;
- funding bodies need to be flexible in negotiating evaluation criteria, and make sure that projects are not overly ambitious;
- longitudinal data are important in effectively measuring the success of a project – commonly used point-in-time evaluation processes are often carried out early in a project and are not so useful; and
- the dissemination and availability of high quality information – both the appropriate methods of evaluation and the results of these evaluations – are important.

Accountability

Key informants noted that, in the past, accountability had often been linked to the financial performance of an organisation and its compliance with the reporting requirements of the funding body. Greater attention was now being given to the need for accountability to Aboriginal and Torres Strait Islander communities. Therefore, in addition to the traditional accountability measures, the following need to be considered in the assessment of programs, projects and interventions:

- how service providers should be accountable to their own communities; and
- the extent to which government funding commitments reflect a greater accountability to communities – based on joint planning, community identified needs and real costs of service delivery.

Key informants acknowledged that appropriate accountability measures – both to funders and to the community – can contribute to the sustainability and success of programs through maintenance of adequate funding and outputs appropriate to community needs.

Capacity building

Capacity building – at community and individual level – was seen by key informants as an important component of most of the other factors. It is an area that needs special consideration in the assessment of the success of specific programs, projects and interventions.

The importance of community, organisational and individual capacity was recognised also by the National Aboriginal and Torres Strait Islander Health Council (2000), which outlined a multi strategic approach to increasing capabilities. The Council saw the capacity of health services and communities to respond to health needs and to take more responsibility for health outcomes jointly as one of nine principles for sustained improvement in Indigenous health (National Aboriginal and Torres Strait Islander Health Council, 2000, p.xiv).

Similarly, the CGC concluded that developing the capacity of Indigenous people to manage service delivery was critical to ensuring they play a central role in decision-making, and in the planning and delivery of services (Commonwealth Grants Commission, 2001). Building capacity is a complex long-term task involving general education and specific training (including managerial training). It requires funding, and is affected by many things (including community social cohesion and strength of culture).

Recognition of the important role of community capacity, which includes characteristics like health literacy, quality housing, community support services, transport, community safety and social support, is relatively recent and is 'currently the focus of considerable research and development' (National Health Performance Committee, 2001, p.12). It is anticipated that this research and development should contribute not only to the assessment of community capacity, but also to greater understanding of the processes for building skills, knowledge and confidence.

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4 Achievements in factors contributing to Indigenous health

4.1 Introduction

As summarised in the section considering the assessment of achievements of the health sector, it is now recognised fully that health depends on a complex interaction of socioeconomic, cultural, environmental and personal factors (biological and behavioural), and the nature and availability of health services (Australian Institute of Health and Welfare, 2000b; Marmot & Wilkinson, 1999; World Health Organization, 2000).

It is now recognised, also, that the poor health status of Indigenous people in Australia is inextricably linked to their poor social, economic and environmental conditions (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001; Australian Institute of Health and Welfare, 2000b).

Thus, a review of achievements in Indigenous health would be incomplete without some attention to achievements in these underlying social, economic and environmental conditions. It was well beyond the scope of this review, however, to undertake more than a superficial analysis of achievements in these areas. The following sections provide brief summarises of these achievements, within which context achievements in health can be viewed.

4.2 Education and employment

Achievements in education and employment for Indigenous people have resulted from specific targeting and the creation of pathways. In Indigenous communities, as in the wider community, educational status is strongly linked to employment status, income and health status, with secondary and tertiary education important in maximising opportunities in life (Commonwealth Department of Health and Aged Care, 2000a). Poor education contributes to poor health in its association with health determinants that have detrimental effects. Disillusionment, poor nutrition and poor health can lead to listlessness, otitis media, poor hearing, language delay and truancy, contributing to a vicious cycle of poor education and poor health (National Aboriginal and Torres Strait Islander Health Council, 2000). Indigenous children have less capacity to take advantage of available opportunities to learn if they are unwell, tired, hungry or emotionally insecure (MCEETYA Taskforce on Indigenous education, 2000; MCEETYA Taskforce on Indigenous education, 2001b). Employment status is the next link in the chain, so it is essential to maximise opportunities for Indigenous people early in life.

There have been a number of achievements in Indigenous eduction in providing: community-controlled institutions; student support initiatives; the provision of Indigenous language and cultural studies; Indigenous education units in tertiary institutions; and a large body of culturally appropriate literature (MCEETYA Taskforce on Indigenous education, 2001b). Many Indigenous people still suffer disadvantage, however, in opportunities for accessing education, and the lack of educational attainment is seen as a contraindication in the Indigenous struggle for self-determination and better health (Tsey, 1997).

The Commonwealth Government outlines in the National Indigenous English Literacy and Numeracy Strategy 2000-2004 its commitment to working with Indigenous families, communities, States, Territories and education providers to overcome educational disadvantages that Indigenous children face (Commonwealth Department of Education Training and Youth Affairs, 2000). In the discussion paper, *Solid foundations: health and education partnership for Indigenous children 0 to 8 years* the relationship between health and educational outcomes is acknowledged (MCEETYA Taskforce on Indigenous education, 2001b). In preparing the discussion paper, which identifies culturally-specific issues and principles relating to community development and capacity building, the MCTEETYA Taskforce on Indigenous education considered advice from international and Australian initiatives on how to improve educational and health outcomes of children at risk. In another discussion paper, *Exploring multiple pathways for Indigenous students*, MCEETYA summarises information on addressing a range of issues to ensure smooth transitions of young Indigenous Australians from school to vocational education and training, and transition to higher education (MCEETYA Taskforce on Indigenous education, 2001a).

Improvements are being achieved in Indigenous educational participation (Australian Parliament Senate, 2000). School retention rates for Indigenous students are still relatively low compared with those for non-Indigenous students, but there have been significant increases over time. Between 1989 and 1997, year 12 retention for Indigenous students increased from 12% to 31%. The number of Indigenous students aged 16 to 17 years participating in school education increased by 40% between 1986 and 1996. During the period 1988 to 1996, the number of Indigenous higher education students more than doubled, and the number of higher education award courses which were completed increased threefold. There have been significant increases in the number of Indigenous mature-age students undertaking education with participation rates among Indigenous people over 30 years of age higher than among the non-Indigenous population.

Recognition of the potential impact of Indigenous health workers is reflected in the creation of pathways into university courses (Aboriginal and Islander Health Worker Journal, 2000). An example is the Bachelor of Health Science, Mental Health at Charles Sturt University in NSW. The course was developed in consultation with the university, health services and the local community as a result of concerns that Indigenous people were not accessing mental health services in southern NSW. Successful graduates have been able to take up positions as mental health workers throughout Australia in both mainstream and Indigenous health services.

Statistics indicate that unemployment within the Australian Indigenous population is at an unacceptably high level, but, according to information collected by the Australian censuses, Indigenous employment grew faster than non-Indigenous employment between the 1991 and 1996.[12] A factor contributing to the high level of unemployment is the fact that 20% of Aboriginal and Torres Strait Islander people live in remote areas, where opportunities for employment are very limited.

There are some encouraging signs to indicate that opportunities are being created to reduce Indigenous unemployment. There are indications of achievements, with the percentage of working-age Indigenous Australians participating in vocational training courses having increased more than five-fold for all age groups. For example, there has been an increase in participation from 4% in 1986 to 22.5% in 1996 in the 18-20 years age group. Higher education enrolments for Indigenous Australians have trebled since the late 1980s, and the proportion employed in professional occupations has increased from 14% in 1986 to 22% in 1996.

Despite these changes, Indigenous people have the lowest economic status of all Australians and are the most disadvantaged in the labour market. Based on information collected by the 1996 census, the median weekly personal income of Indigenous people in 1996 was $218, well below the weekly income of $294 for the total population (Australian Bureau of Statistics, 1998). Median weekly household income was lower for Indigenous households ($540) than for other households ($632), despite Indigenous households being larger.

There is a strong association between labour force participation and health, with unemployment, job insecurity and uncertain financial circumstances all associated with adverse health outcomes (National Health Performance Committee, 2001). Workforce issues are thus critical to improving Indigenous health. There is a lack of data, however, with which

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[12] Some caution should be exercised in the interpretation of these rates, however, as the Community Development Employment Projects scheme (CDEP) is the main source of employment for Aboriginal and Torres Strait Islander people in rural areas. The CDEP is a scheme which offers unemployed Indigenous Australians the opportunity of working in community-managed projects and enterprises if they forego unemployment-related social security entitlements.

to monitor the situation and the complex interactions between education organisations, professional bodies, service providers and governments (Commonwealth Department of Health and Aged Care, 2001).

According to Australian Workplace, approximately 28% of Indigenous work opportunities lie in the public sector, with 70% of Indigenous jobs relying on public funding in some way (Australian Workplace, n.d.-b). Given that the greatest labour growth is within the private sector, initiatives in this area are paramount. These factors are recognised in the Commonwealth Government's 'Indigenous Employment Policy' (Australian Workplace, n.d.-b). Under this policy, several projects have been implemented to generate more employment opportunities for Indigenous people, particularly in the private sector. The policy seeks also to develop and expand Indigenous small business opportunities.

The Corporate Leaders for Indigenous Employment Project, which has been implemented under this policy, has seen several private sector corporations generate placements and trainee positions specifically for Indigenous people (Australian Workplace, n.d.-a). Over fifty companies have committed to improve the employment prospects of Aboriginal and Torres Strait Islanders. The first company to sign this agreement was Chubb Protective Services, committing to 120 places. Since then, other companies that have become involved include Rio Tinto, Eurest Australia, Western Mining, and Normandy Mining.

With a large proportion of the Indigenous population living in remote areas of Australia, where employment opportunities are limited, it is encouraging to note that placements have been made possible under this policy (Australian Workplace, n.d.-b). Pasminco Century Mine in north Queensland has worked hard to increase its Indigenous workforce by employing and training up to 95 unemployed people from remote communities in the lower Gulf of Carpentaria. This intake would reportedly increase Pasminco's Indigenous workforce to over 20% with plans for further increase.

It has been reported also that nineteen graduates have been successfully employed by Kakadu Tourism, as a result of a Commonwealth agreement with Kakadu Tourism to employ and train 22 Indigenous people in the tourism industry (Australian Workplace, 2000). This venture included a twelve-week training course with the Northern Territory University, and on-the-job training through hotels operated by Kakadu Tourism. The program has achieved success in retaining employees with Kakadu Tourism and for providing pathways for the trainees into permanent employment in a range of industries.

The Indigenous Employment Service has kept abreast of the latest technology in the development of a website offering a free on-line service that helps match employers with Indigenous job seekers. Job seekers have the facility to lodge their resumé and details and/or search for employment. In turn, employers can then look for appropriately skilled staff or advertise any available position (Australian Workplace, 2000).

Consideration must be given also to the retention rates of Aboriginal and/or Torres Strait Islander people once they are in position in mainstream employment or mainstream teaching institutions. This can be greatly impacted on by the respect given to Indigenous culture and on the importance of support networks, which need to be in place to support Indigenous people and their culture (Angus, 1998).

With education and skill development as key factors in ensuring sustainable employment, it encouraging to note that several organisations have committed to the recruitment and training of Aboriginal and Torres Strait Islander people. Examples of this achievement can be seen with the development of strategies such as those implemented by the University of Technology Sydney and Queensland Health.

Queensland Health recognises that, to improve the health status of Aboriginal and Torres Strait Islander people, it is imperative for Indigenous people to be recruited, retained and provided with career pathways through its workforce. In its commitment to improving the health status of Indigenous people, it will contribute to the State Government's Indigenous employment target of 2% by the end of 2002 and of 2% across all salary levels by 2010

(Queensland Health, 1999). It is recognised also that strategies to increase secondary and tertiary education completion rates are necessary to create improved Indigenous applicant pools for jobs. Queensland Health is committed to working with and developing partnerships with a variety of government departments, the vocational education and university sector, health professionals, key stakeholders (including Indigenous communities) and others to achieve these targets.

The University of Technology Sydney is committed also to Indigenous employment through a number of strategies, which ensure opportunities for Indigenous people (University of Technology Sydney, n.d.). These include pro-active strategies which focus on: recruiting, retaining and development of Indigenous employees; development of Indigenous academic programs; electives for both Indigenous and non-Indigenous students; promoting access to employment opportunities for Indigenous graduates and students of the University; and developing partnerships with other universities, industry and agencies to promote Indigenous employment.

4.3 Housing and the environment

The literature suggests that various programs and interventions are working to improve the status of housing conditions for Indigenous populations (Sanders, 2000). None of these programs are without problems – nor do they provide housing solutions for all Indigenous people in all life circumstances – but they are significant developments which have provided a new and expanded range of housing possibilities for Indigenous people. If critically evaluated and built upon, these programs could lead to a better future in Indigenous housing.

Measuring achievements and successes in the area of housing is problematic and subjective in some cases. Thus, it should be acknowledged that certain areas and elements of success will not be moulded into specific measurable outcomes. Recording the status of housing for Indigenous people is necessary even if not complete. *The Australian Housing Survey 1999* provides general housing information, with an Indigenous household defined as any household containing at least one person of Aboriginal and/or Torres Strait Islander origin aged 15 years or over (Australian Bureau of Statistics, 2001). The ABS has also conducted a housing survey, *Community Housing and Infrastructure Needs* (Australian Bureau of Statistics, 2000). Information is also included in the *Agreement on national Indigenous housing information* (Australian Institute of Health and Welfare, 2000a).

Community control and participation are areas within the housing arena that have displayed improvements and recent achievements. Examples of these can be seen throughout an array of recent programs, which have not only increased community control and participation, but have led also to improvements in community management and self-determination. Building capacity to improve living conditions can also lead to the conditions being more appropriate for Indigenous people and to a sense of ownership and pride (Aboriginal Housing, 1999). Indigenous involvement in decision-making processes, and representation on various housing and infrastructure boards of management has increased over recent years, and as a result, many housing programs now meet community needs. The Indigenous Housing Authority of the Northern Territory (IHANT) plays an important role in maximising housing outcomes for Indigenous Territorians, through managing housing stock efficiently, while providing a healthy living environment for tenants (Commonwealth Department of Health and Aged Care, 2000b). A key factor contributing to the success of the Authority is the Indigenous majority in its membership. The benefits of programs put forth by the Authority can be seen in increases in Indigenous consultation, self-determination and self-management.

There are other examples of projects with increased community control and participation. These include

- the Uwankara Palyanyku Kanyintjaku ('stop people from getting sick') project in the Anangu Pitjantjatjara Lands of SA (Pholeros, Rainow, & Torzillo, 1993). The project relied on community involvement in the development of a list of nine healthy living practices, which have been previewed in the National Indigenous Housing Guide as prepared by Healthhabitat.

- the Port Augusta families' project in SA has been successful in not only increasing the empowerment of community members, but also in achieving a greater number of parents who are paying debts for electricity, housing and other services (McCallum, 2000).
- in Goodooga, NSW, the self-constructed housing paradigm offered a lifestyle and degree of flexibility that was highly desired by most Indigenous people in the community, and has resulted in residents maintaining a strong sense of pride and control over their environment (Smith, 2000).

Many of the recent projects, which are concerned with improving housing conditions and standards, are effective in developing strong working partnerships with the communities. Pholeros and colleagues have identified that any program designed for the Indigenous community has to involve Indigenous people if it is to get any community support (Commonwealth Department of Health and Aged Care, 1999). The literature suggests that encouraging the community to be involved in the development of housing standards is essential. Involvement of Indigenous people in the decision-making and legislative processes is identified in all of the successful programs which have been reviewed, as they encourage community ownership and community management plans (Commonwealth Department of Health and Aged Care, 1999).

The literature demonstrates also that there have been marked achievements in the development of the Indigenous workforce in relation to housing and infrastructure. The Western Australian Aboriginal Housing Board provides an example of customer support services from Indigenous officers, who assist Indigenous people make a success of their Homeswest tenancy (through improving community management), and who act as cultural bridges between staff in Perth and Indigenous people who are experiencing tenancy problems (Aboriginal Housing, 1999).[13]

The *Fixing Houses for Better Health* (FHBH) project employs local Indigenous community teams to carry out maintenance work on houses located in rural and remote areas of Australia (Pholeros, 2001). In the Far West Area Health Service (FWAHS) of NSW, Aboriginal Trainee Environmental Health Officers (TEHOs) are involved with the *Housing for Health* project, as they work with community members to carry out housing surveys to determine what needs fixing for each house within the community. These programs have been very successful where TEHOs are involved. The community consultation and the interaction with the community have increased and employment outcomes have improved (Irvine, 2001).

Indigenous employment programs, such as the CDEP scheme, are encouraged to tender on works coupled with *Housing for Health* projects – to generate income and place them on a commercial footing (Irvine, 2001). As a result, there are now many community members who have established work with local tradespeople. Through the Indigenous Housing Authority of the NT (IHANT), employment and training outcomes for Indigenous people in remote communities have been generated, providing Indigenous building and construction teams to participate in the delivery of maintenance programs (Hill, 2001). Through this type of involvement, Indigenous people are gaining skills in building construction, repairs and maintenance. Additionally, the employment of Indigenous people provides a better socioeconomic outlook for remote Indigenous communities (Hill, 2001).

In summary, the examples discussed above display that, where possible, local skills should be identified, developed and utilised to maximise successes in this area.

The development of partnerships has been an important factor in the area of Indigenous housing. In the NT, there has been greater coordination between the Indigenous Housing

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[13] Homeswest is the Western Australian Government agency that provides rental accommodation for families on low incomes.

Authority of the NT (IHANT) and the National Aboriginal Health Strategy program (NAHS), which in turn has improved coordination between programs (Morton, 2001).

The partnership, in the Broome area of WA, between members of Outreach Australia (ORA), the Beagle Bay community, the Ladjardarr Bay Aboriginal Corporation, and the Goolarabooloo people emphasised the importance of collaboration and the necessity to listen to the people (Saunders, 1999). The resultant 'settlement planning principles' are more culturally appropriate to Indigenous housing needs.

The development of partnerships continues to be a high priority for the South Australian Aboriginal Housing Authority, and, as a result, both achievements and initiatives in this area have occurred. Formal links established with Aboriginal Hostels, Nuga Minimis, Nunkuwarrin Yunti and the Department of Human Services Justice Strategy Unit, have provided benefits for the AHA and its customers (Aboriginal Housing Authority, 2000).

The value of partnerships in the area of housing is important to all aspects of decision-making on how housing issues should be addressed. As a collaborative initiative of the Commonwealth State and Territory governments, a *National Framework for the design, construction and maintenance of Indigenous housing* has been developed (Commonwealth Department of Family and Community Services, 1999). This particular framework has been an important achievement, and complements mainstream regulatory building mechanisms in ensuring national principles of health, safety, quality control and sustainability (Commonwealth Department of Family and Community Services, 1999).

The Agreement for the provision of essential services to Aboriginal communities in Western Australia was signed by ASTIC, the Western Australian Government and the Commonwealth Minister for Aboriginal and Torres Strait Islander Affairs in October 2000 (The Government of the Commonwealth of Australia, Aboriginal and Torres Strait Islander Commission, & The Government of the State of Western Australia, 2000). This agreement formalises a joint approach between ATSIC and the WA State Government in aiming to provide more efficient and effective service delivery of essential services to Indigenous communities. It also aims to improve environmental health outcomes, while seeking to complement existing housing and health bilateral agreements.

Another joint initiative reflecting the appropriateness of partnerships is that formed by the Environmental Health Needs Committee in WA. This partnership involves Homeswest, ATSIC, the WA Aboriginal Affairs Department, the Commonwealth Department of Health and Aged Care and the Western Australian Municipal Association (Ove Arup and Partners, Smith and Hooke Architects, Healey Engineering, d'ENVIRO Health, & Morton Consulting Services, 2000). The partnerships has assisted in the development of a *Code of Practice for housing and environmental infrastructure development in Aboriginal communities in Western Australia*. This Code of Practice provides the framework within which sustainable improvements to the design and durability of housing and environmental infrastructure in Indigenous communities can be achieved and maintained.

Settlement planning offers alternative ideas about housing, planning and community development, and proposes that people's living environments should be designed according to their culture, society and location. Over recent years, there has been a gradual shift of focus in housing design concepts, and increasing realisation that solutions to housing problems are to be found within Indigenous communities themselves (Sinatra & Murphy, 1997). Settlement planning and community development projects can help improve health issues – by responding to people's needs according to lifestyle, family, country, generation and sociality. The Family Camp House concept is a response to the need for a different approach to Indigenous housing, which acknowledges the landscape is an essential component of the living environment (Saunders, 1999). This concept, which has been established in three areas of Australia – Beagle Bay (WA), Kintore (NT) and Old Mapoon (Qld) – can contribute to future planning directions for rural and remote Indigenous communities (Sinatra & Murphy, 1997).

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5 General achievements in Indigenous health

5.1 Infrastructure for Indigenous health

Background

In the report of its recent inquiry into Indigenous health, the House of Representatives Standing Committee on Family and Community Affairs concluded that 'the major difficulty in implementing the key recommendations from these reports [previous reports on Indigenous health] has been the lack of any clear consensus about which tier of government is responsible for Indigenous health matters….this is compounded by the lack of coordination between Commonwealth, State and Territory health and related services, and between programs within each of these jurisdictions' (House of Representatives Standing Committee on Family and Community Affairs, 2000, pp.8-9). The related recommendation was:

> The Commonwealth take a more active role in the planning, delivery and monitoring of health and related services for Indigenous Australians, if progress is to be made in improving Indigenous health. This role will need to be formalised in agreements with the States, Territories and communities (House of Representatives Standing Committee on Family and Community Affairs, 2000, p.9).

The Committee also emphasised a key role for the Indigenous community-controlled health sector, including NACCHO.

It is clear that the issues identified by the Committee have hampered efforts in addressing Indigenous health, but substantial progress has been made on these issues since at least the mid 1990s. Major changes have been made in a number of State and Territory health authorities, but there is little published information about these achievements. Fortunately, there is more information about the changes at Commonwealth level and in national mechanisms for addressing Indigenous health. These achievements will be summarised in the next sections of this review.

Commonwealth

Since the mid 1990s, the Commonwealth has taken a much more pro-active role in Indigenous health. As noted by the Australian National Audit Office, the Commonwealth 'decided that it was necessary to develop a national and strategic approach to the planning and delivery of primary health services to Aboriginal and Torres Strait Islander peoples, to clarify roles and responsibilities with the Commonwealth – and between the Commonwealth and the States – for the delivery and funding of services, as part of new measures to achieve change. The advantages for Aboriginal and Torres Strait Islander communities were envisaged as being an approach which reduced administrative complexity, fostered community control and accountability, and encouraged longer-term planning by communities to address local health needs' (Australian National Audit Office, 1998, p.11).

The transfer in 1995 of responsibility for the delivery of the Commonwealth Aboriginal and Torres Strait Islander health program from ATSIC to the Department of Human Services and Health (now Department of Health and Ageing) was seen as an important part of this process. The transfer was accompanied by a substantial expansion of the Department's Office for Aboriginal and Torres Strait Islander Health (OATSIH), which had been established to give a greater focus on the health needs of Indigenous Australians in mainstream health programs (Office for Aboriginal and Torres Strait Islander Health, 2000).

OATSIH's strategic approach involves:

- achieving comprehensive and effective health care for Aboriginal and Torres Strait Islander people through the development of infrastructure and resources;
- addressing key health issues and risk factors impacting on health status;
- improving the evidence base through effective data systems and evaluation, and promoting the use of effective policy ; and

- improving communication with service providers, governments and the general population.

To address the possible disjunction between health and health-related programs (such as housing and other physical environmental aspects) at Commonwealth level, a Memorandum of Understanding (MOU) was developed between ATSIC and the Commonwealth Department of Health and Aged Care (now Department of Health and Ageing). The initial MOU, which expired on 30 June 2000[14], included two focal points: national policy development, and program planning (Aboriginal and Torres Strait Islander Commission, 2001; Australian National Audit Office, 1998).

States and Territories

As noted above, there is little published information about the major changes that have occurred in a number of State and Territory health authorities. As a result, it has not been possible to summarise information about achievements related to administrative changes in the States and Territories.[15]

The Aboriginal community-controlled health sector

All major reports in recent years have stressed the role of the Aboriginal community-controlled health sector, and there are now around 200 community-controlled health and substance misuse services.

In parallel with the growth of local Aboriginal community-controlled health services (ACCHSs), NACCHO has developed its role in national advocacy for these services and for Indigenous health more generally. NACCHO, the umbrella organisation representing Aboriginal community-controlled health services (Commonwealth Department of Health and Aged Care, 2000a), was established in 1993, replacing the National Aboriginal and Islander Health Organisation (NAIHO) which had been relatively inactive for a number of years. NACCHO is assisted in its work by a network of affiliated organisations in most States and the NT. In providing links among ACCHSs, and between ACCHSs and the government, the work of NACCHO and its affiliates includes:

- promoting, increasing, developing, and expanding the provision of medical and health services through local Aboriginal community controlled primary health care services;
- liaising with governments, departments, and organisations within both the Aboriginal and non-Aboriginal community on matters relating to the wellbeing and health of Aboriginal communities;
- representing and advocating for Aboriginal communities in matters relating to health services, health research, health programs, etc;
- assisting member organisations to provide Aboriginal people with medical services and other health services; and
- assessing the health needs of Aboriginal communities (through research, data analysis, surveys, etc), and taking steps to meet these needs (NACCHO, 2002).

The growth and development of NACCHO, its affiliates and community-controlled health and substance misuse services are substantial achievements, which should contribute to measurable achievements in specific health outcomes.

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[14] The ATSIC annual report for 2000-01 noted that negotiations for a new MOU were underway (Aboriginal and Torres Strait Islander Commission, 2002).

[15] As with other aspects of this review, the collation of this information would be valuable, and should be documented at some stage.

National mechanisms

Framework agreements

Major advances in the administrative infrastructure for Aboriginal and Torres and Islander health include the *Agreements on Aboriginal and Torres Strait Islander Health* (Framework Agreements), which facilitate joint planning between governments and Indigenous organisations.

Agreements were negotiated between the Commonwealth Government, State and Territory governments, ATSIC (or the Torres Strait Regional Authority (TSRA) in the Torres Strait Agreement) and the NACCHO State or Territory affiliate body. These Agreements were signed in each State and Territory and the Torres Strait between 1996 and 1999 and committed signatories to four key areas:

- increasing the level of resources allocated to reflect the level of need;
- joint planning;
- improving access to both mainstream and Aboriginal and Torres Strait Islander specific health and health-related services; and
- improving data collection and evaluation.

The Framework Agreements also established a number of formal structures and processes to enable action to be undertaken at State/Territory and national levels. These include the National Aboriginal and Torres Strait Islander Health Council and planning forums (health forums) in each State and Territory. At the August 1999 Australian Health Ministers' Conference (AHMC) meeting, Health Ministers agreed in principle to extend the Framework Agreements after they expired on 30 June 2000 (National Aboriginal and Torres Strait Islander Health Council, 2000).

Positive outcomes from the Framework Agreements identified by NACCHO include: improved intersectoral communication and collaboration in several States and Territories; joint Indigenous health regional plans; and resourcing for NACCHO and most of its State/Territory affiliates (Commonwealth Department of Health and Aged Care, 2000a).

National Aboriginal and Torres Strait Islander Health Council

As part of the developing collaboration between the Commonwealth, States, Territories and the Aboriginal community-controlled health sector, the National Aboriginal and Torres Strait Islander Health Council was established in 1996 to advise the Commonwealth Health Minister on Aboriginal and Torres Strait Islander health policy and planning and to monitor the national implementation of the Framework Agreements (Australian National Audit Office, 1998).

Following a re-structure in March 1999, membership of the Health Council now includes representatives from each of the Framework Agreement partners (the Commonwealth, States and Territories, ATSIC, the Torres Strait Regional Authority and NACCHO) and from the National Health and Medical Research Council (NHMRC) (ex-officio), the Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN), and the Australian Indigenous Doctors Association. The Council also has as members, appointed by the Minister in their own right, an expert on Indigenous substance use issues and two other experts on Indigenous health.

One of the Council's key roles recently was to oversee development of the National Strategic Framework for Aboriginal and Torres Strait Islander Health (known formerly as the National Aboriginal and Torres Strait Islander Health Strategy), which is intended to build on the progress made since the development of the 1989 National Aboriginal Health Strategy.[16]

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[16] The *Draft National Aboriginal and Torres Strait Islander Health Strategy* considers a multi-strategic approach to increasing capabilities within Indigenous health. Building the capacity of health services and communities to respond to health needs and to take more responsibility for health outcomes are seen jointly as one of nine principles for sustained improvement. Creating healthy communities requires strengthening health services and building on community expertise. In the health sector, requirements are: reforming health

A draft was released in February 2001 for public comment. Based on this feedback, the strategy will be provided to Framework Agreement partners for comment prior to the Council submitting it to Health Ministers for Cabinet endorsement in each jurisdiction.

Standing Committee on Aboriginal and Torres Strait Islander Health

At its 25 October 2001 meeting, AHMAC (Australian Health Ministers' Advisory Council) agreed to establish the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH) with the following draft terms of reference to:

- assist AHMAC to meets its whole-of-health system responsibilities to improve Indigenous health;
- coordinate and promote jurisdictional activities in relation to Indigenous health policy development, program development and delivery;
- provide advice to and representation on the National Aboriginal and Torres Strait Islander Health Council;
- provide a forum for coordination of health jurisdictions' advice on Indigenous health to COAG (Council of Australian Governments) and other Ministerial Councils; and
- convene a forum responsible for personal development, leadership and collegiate development of Indigenous staff working within Commonwealth, State and Territory health departments (Australian Indigenous Health*InfoNet*, 2001).

The SCATSIH supersedes the Heads of Aboriginal Health Units (HAHU) forum.

Summary

It is clear that substantial progress has been made in recent years on two areas highlighted by the House of Representatives Standing Committee on Family and Community Affairs as contributing to the failure of Australia to achieve better health outcomes for Indigenous people:

- lack of any clear consensus about which tier of government is responsible for Indigenous health matters; and
- lack of coordination between Commonwealth, State and Territory health and related services, and between programs within each of these jurisdictions (House of Representatives Standing Committee on Family and Community Affairs, 2000).

The Framework Agreements should facilitate joint planning between governments and Aboriginal and Torres Strait Islander organisations within each jurisdiction.

At a national level, the establishment of the National Aboriginal and Torres Strait Islander Health Council should provide a mechanism for the oversight of policy issues as well as monitoring the Framework Agreements. The more recent establishment of SCATSIH should ensure better coordination between the Commonwealth, State and Territory governments in terms of health and related services.

At a Commonwealth level, the much greater attention directed to Aboriginal and Torres Strait Islander health since the mid 1990s should also assist the achievement of better health outcomes for Indigenous people. As with many other areas of Indigenous health, it is too early to expect much in the way of measurable outcomes, but, for the first time, Australian is now moving towards national policies and strategies for a variety of health conditions (see, for example, the developments in national strategies for alcohol-related problems (Commonwealth Department of Health and Aged Care, 2000b) and the Indigenous health

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systems; financial investment; devolving resources and decision-making to communities and increasing the Aboriginal and Torres Strait Islander workforce. Aboriginal and Torres Strait Islander leaders are aware that self-determination and mutual responsibility underpin strategies for improving the health of their communities. Growing evidence demonstrates that increasing control and social cohesion increases the capacity of individuals, families and communities to make healthy choices. For Indigenous people, there have been losses of social cohesion through relocation from traditional lands and policies of assimilation. Communities need information about the health system and health issues, support to articulate their community, family and individual health priorities and the power to make meaningful choices between program options and providers (National Aboriginal and Torres Strait Islander Health Council, 2000).

workforce (Office for Aboriginal and Torres Strait Islander Health, 2001)). The coordination of health and health-related programs at a Commonwealth level should be facilitated by the MOU between ATSIC and the Commonwealth Department of Health and Ageing.

Considerable progress appears to have been achieved also in the role of the Aboriginal community-controlled health sector. This is seen in the expanded availability of community-controlled primary health and substance misuse services. It is seen also in the growth and development of NACCHO and its State and Territory affiliates. NACCHO, in particular, is playing an important role in policy and program development at national and State/Territory level.

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5.2 Access to appropriate services

Background

The most important aspect of the effectiveness of health systems for Indigenous people is concerned with the adequacy of access to the health services they require (Office for Aboriginal and Torres Strait Islander Health, 2000), where accessibility can be defined as the 'ability of people to obtain health care at the right place and right time irrespective of income, cultural background or physical location' (National Health Performance Committee, 2001, p.8).

Cultural, educational, linguistic and lifestyle factors prevent some Indigenous people feeling comfortable attending a private general practice or a hospital, and sometimes they will only do so if there is no alternative or their health problem has become extreme (Aboriginal and Torres Strait Islander Commission, 2001; Commonwealth Department of Health and Aged Care, 2000). Indigenous people may also experience financial barriers if the practice does not bulk bill. Physical access barriers, such as distance and lack of transport, may also prevent access (particularly for Indigenous people living in remote areas). Understanding the educational, linguistic and lifestyle norms of Aboriginal and Torres Strait people will assist in providing more effective health care (Australian Institute of Health and Welfare, 2001).

The geographical distribution of Indigenous people is quite different to that of non-Indigenous people. The proportion living in remote and very remote regions is ten times that of other Australians, according to the Accessibility/Remoteness Index of Australia (ARIA)[17] (Australian Institute of Health and Welfare, 2001). Less than one-third of the Indigenous population lives in major urban centres (where access to all mainstream services is available), and one in five resides in remote settings, away from centres with basic health facilities (de Looper & Bhatia, 2001).

Mainstream services may not be culturally appropriate and, as noted above, are often provided at locations distant for Indigenous peoples. Few Aboriginal or Torres Strait Islander people visit a general practitioner as a first point of call within the health care system (National Aboriginal and Torres Strait Islander Health Council, 2000). The *Bettering the Evaluation and Care of Health* (BEACH) survey describes the under-utilisation of general medical practitioners by Indigenous people, compared with other Australians (Australian Institute of Health and Welfare, 2000; Britt et al., 2000).

General practitioners have an important role, however, in breaking the cycle of Indigenous disadvantage by providing appropriate, high quality health care to Indigenous communities and individuals (Commonwealth Department of Health and Aged Care, 2000). As well as their core roles, research has demonstrated that physicians and other health professionals can be important advocates for change in the delivery of health services, public health policy and other community wide initiatives (Office for Aboriginal and Torres Strait Islander Health, 2000).

Aboriginal community-controlled health services

In 1971, the Redfern Aboriginal community developed the first Aboriginal community-controlled health service (ACCHS) (Australian Indigenous Health*InfoNet*, 2001). Since then, the number of ACCHSs around Australia has increased steadily, and there are now around 200 community-controlled health and substance misuse services.

As defined by NACCHO, ACCHSs must be:

- incorporated Aboriginal organisations;
- initiated by the local Aboriginal community;
- based in an Aboriginal community;

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[17] The ARIA is a system that classifies localities according to an indicator of the accessibility of services (distance from service centres), into five categories: highly accessible; accessible; moderately accessible; remote and very remote.

- governed by an Aboriginal board of directors that is elected by the local Aboriginal community; and
- deliver holistic and culturally appropriate health services to the community.

In its submission to the inquiry into Indigenous health, NACCHO noted that adequately resourced ACCHSs can deliver significantly better services than other options because delivery is flexible, responsive and cost effective in addressing local priorities (House of Representatives Standing Committee on Family and Community Affairs, 2000). The inquiry's report recommended that the Commonwealth should support increased community control of health services for Indigenous communities with the community having responsibility to determine the nature of the control. The Commonwealth responded that it had pursued the principle through funding community-controlled services (Commonwealth Department of Health and Aged Care, 2001e).

ACCHSs are also culturally secure and appropriate because Indigenous people manage the organisation and are the employers of non-Indigenous staff. The overall effectiveness of community-controlled services is dependent on the level of funding available. Some services have struggled to receive the funding they need. NACCHO considers that a properly resourced community-controlled health service can deliver:

- significantly improved access;
- the full range of primary health care services in one place – integrated, culturally appropriate and holistic care;
- value for money, as services are better targeted (being based on local knowledge);
- a major source of education and training for Indigenous people; and
- a pool of knowledge and expertise about Indigenous health enabling the sector to not only deliver appropriate care but also to advocate effectively for Indigenous people in health (House of Representatives Standing Committee on Family and Community Affairs, 2000).

Coordinated Care Trials

The Aboriginal and Torres Strait Islander Coordinated Care Trials were conducted with the aim of achieving a more coordinated approach to the delivery of health care services to people with a diverse range of complex and chronic health care needs. They were conducted in Katherine (NT), the Tiwi Islands (NT), Wilcannia (NSW) and Perth/Bunbury (WA). Evaluation at local and national levels was carried out, the trial outcomes included: enhanced service access with financial flexibility provided through funds pooling and MBS/PBS funding; improved service appropriateness; significant progress in the development and implementation of organisational structures and processes; improved individual empowerment and greater understanding of the importance of community empowerment as a vehicle for health service reform. Factors that inhibited progress included: geographical location; conditional funds pooling; limited investment in local decision making capacity; limited service options; workforce shortages and limited infrastructure (Commonwealth Department of Health and Aged Care, 2001a; Commonwealth Department of Health and Aged Care, 2001b; Commonwealth Department of Health and Aged Care, 2001c).

Achievements

Success in health service provision has been achieved in overcoming barriers to the access of services, including services in rural areas. The availability of interventions in appropriate settings has also been an achievement. Progress has been made in the provision of community-controlled organisations, encouraging community participation and increasing the accessibility and appropriateness of mainstream health services to Indigenous people. The latter aspects are important, because many Indigenous communities and people do not have access to an ACCHS – nearly 80% of all primary and secondary care services for Indigenous people are managed by the State and Territory (House of Representatives Standing Committee on Family and Community Affairs, 2000).

Aboriginal community-controlled health services

As noted above, there are presently around 200 community-controlled health and substance misuse services around Australia. Around 130 of these are ACCHS and the remainder are substance misuse services. The number of ACCHSs has increased from around 30 in 1984 and around 60 in 1995, when responsibility for Indigenous health at the Commonwealth level was transferred from ATSIC to the Department of Health and Ageing (House of Representatives Standing Committee on Family and Community Affairs, 2000). After noting that the ACCHSs 'are distributed fairly unevenly' across the States and Territories, the inquiry into Indigenous health concluded that 'this reflects the largely historical, and generally unplanned, nature of the decisions to fund each of the individual services' (House of Representatives Standing Committee on Family and Community Affairs, 2000, p.36).

The impact of the Aboriginal community-controlled health sector is being demonstrated through health gains, such as measurable improvements in immunisation rates and reductions in sexually transmitted infections in several areas (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997) (Miller, Torzillo, & Hateley, 1999). As well as offering a range of health services (including general and specialist services, and those addressing remote health, eye health, hearing, substance use, sexual health, mental health and emotional wellbeing, and transport) (Australian Institute of Health and Welfare, 2001), the ACCHSs also represent a major source of education, training, achievement and pride (National Aboriginal and Torres Strait Islander Health Council, 2000). Specific achievements of individual ACCHSs and their 'umbrella' groups (such as NACCHO) are not summarised here, but in other relevant sections of this review.

Community participation in specific health projects

In the report *Promoting the health of Aboriginal and Torres Strait communities* (National Health and Medical Research Council, 1997), case studies of various projects involving community participation are described, including analysis of contributors to success. The following summaries are taken from that publication.

Garden Kai Kai Project, Thursday Island, Torres Strait Islands. This program addressed nutrition needs of a community. The following success factors were identified:

- needs were identified by the community and met by a program managed by the community and health workers;
- development of trust and respect between non-Indigenous and Indigenous staff; and
- there were clear goals and everyone was kept informed.

Heatworks, Kimberley Aboriginal Medical Service, Western Australia. A travelling theatre show uses story telling, dance, music, and song to pass on health messages. The following success factors were identified:

- mobile program travelled to the people by invitation;
- tours respected community commitments such as funerals and law, and the team did not enter if the time was inappropriate;
- used simple, local language; and
- Aboriginal ownership wherever possible.

Koori Heart Health Screening Program, Greater Murray Area Health Service, New South Wales. The program provides screening for heart diseases and referrals for further treatment where necessary. The following success factors were identified:

- Aboriginal Health Workers and community health workers and the Aboriginal community had built up a rapport and, thus, trust and respect each other;
- the material developed was presented in a culturally effective, culturally sensitive way and owned by each particular community; and
- health workers provided a strong bridge between Aboriginal people and the mainstream health services, helping to build a more trusting, respectful relationship enabling Aboriginal people to have access to the health care services they need.

Ngua Gundi-The Mother/Child Project, Woorabinda, Queensland. This project investigated the reasons for poor attendance at the antenatal clinics and aimed to re-orient health services for young women during their pregnancies and following the birth of their babies. The following success factors were identified:

- recognition of history and the effect of colonisation;
- recognition of a need for a holistic, coherent and culturally sensitive health service;
- recognition of the need for building strong, healthy partnerships between services and organisations that have a role in delivery of health care services and promoting health;
- clear goals and AHWs involved in planning, implementation and evaluation at all stages of the project; and
- the program was well supported by management and resources were available.

Aboriginal Sexual Health Program, Greater Murray Health Service, New South Wales. This community education program addressed sexual health issues, including HIV/AIDS. The following success factors were identified:

- the consultation process and the development of partnerships between AHWs, Aboriginal communities, Greater Murray Area Health Service, South West Centre for Public Health, NSW and Victorian Aboriginal Health Branches;
- listening to what communities' needs were regarding sexual health;
- ongoing, culturally appropriate training and support to AHWs and mainstream workers gave them confidence to work in this area; and
- the project was adequately resourced.

Training for Aboriginal Health Workers in submission writing and project management, Queensland University of Technology, Queensland. This program provided Aboriginal Health Workers with training in submission writing and project management skills, using the principles of health promotion. The following success factors were identified:

- the community had clear ideas about improving their health and Queensland Health recognised that Indigenous health workers had specific and unique needs requiring them to be involved in the planning, the implementation and the evaluation of all projects;
- health workers supported each other while gaining new knowledge; and
- the project was adequately resourced.

Control of Japanese encephalitis (JE), Torres Strait Islands, North Queensland. This program aimed at increasing knowledge of Japanese encephalitis, improving vaccination rates and the control of risk factors for the disease (such as developing plans for piggeries, cleaning drains and septics, providing insecticide treatments). The following success factors were identified:

- partnerships and intersectoral action to address social and physical risk factors;
- health workers involvement in education about personal protection, vaccination, and the production of posters, T-shirts and information pamphlets;
- cooperation with the local media, radio and newspaper to increase knowledge about JE; and
- adequately resourcing.

The Gubba Binbee nGoodjida Inda Diabetes and Nutrition Project, Rockhampton, Queensland. A pilot program identified the need for a diabetes and nutrition program, which was designed and implemented by an Aboriginal health team. The following success factors were identified:

- the program addressed issues of lifestyle and behaviour change as a priority to empower Indigenous people to control diabetes and reduce their likelihood of developing complications;
- recognition that a strong sense of community ownership is developed when community members take an active role in their own health care, in partnership with AHWs, medical and nursing staff. This means it is more likely that people can succeed in making changes in their lives, including ensuring that the health care services they need are available;

- the pilot program identified the need for services to be culturally acceptable, and education needed to be provided in ways that supported learning and did not judge or criticise people;
- success depended upon people participating – unless the program was acceptable and accessible it would not have succeeded. The principles of primary health care mean that the program is more likely to be sustainable; and
- the health workers ensured that there was effective communication among all groups involved.

In summary, Indigenous health workers played a key role in working with communities to identify community concerns and to establish whether people wanted to take action. The programs were responsive to the culture, needs and circumstances of individual communities. Effective working partnerships between AHWs, non-Indigenous health workers, communities and organisations were important. Respect for each other and the sharing of knowledge and skills were combined in learning processes. Each program was adequately resourced and, and as a result of their success, was able to secure ongoing funding (even though funding did remain a significant problem due to tight budgets). It was noted that time-frames were too short to expect measurable changes in mortality and morbidity, and that funding was insufficient to enable evaluation at that level. Importantly, the success of projects such as these should be judged also by the communities themselves.

Mainstream programs

Achievements in access have also resulted from Indigenous-specific initiatives in mainstream programs.

The Medical Benefits Scheme has removed impediments to access for Indigenous people by reviewing and making changes to entitlement criteria and enrolment procedures. For example, an exemption has been made under Section 19(2) of the *Health Insurance Act 1973* to allow salaried doctors in approved services to bill Medicare, thus assisting in the provision of comprehensive primary health care (Commonwealth Department of Health and Aged Care, 2001d).

Better access to the Pharmaceutical Benefits Scheme (PBS) is being achieved through the use of Section 100 of the National Health Act. The Minister has approved arrangements for remote services to order pharmaceutical supplies in bulk through community pharmacies that comply with relevant government legislation (Commonwealth Grants Commission, 2000). Government and non-government health services in remote areas are able to be supplied with PBS medicines on a bulk supply basis through community pharmacy, which is then reimbursed by the Health Insurance Commission (Commonwealth Department of Health and Aged Care, 2000). The scheme provides an opportunity to build local partnerships between health services and community pharmacies in the quality use of medicines.

A number of other Commonwealth initiatives contribute to Indigenous health through mainstream services. These include the university departments of rural health and rural clinical schools, the Regional Health Services Program, continued expansion of the Multipurpose Services Program, and support of designated primary care services for Indigenous people through the Divisions of General Practice (Commonwealth Department of Health and Aged Care, 2001d).

The report *Stocktake of Indigenous-specific and mainstream health programs impacting on Indigenous people* provides details of a wide variety of initiatives, need-related factors and achievements since 1996 (Office for Aboriginal and Torres Strait Islander Health, n.d.). *Lookin' after our own* details the story of the Aboriginal Family Support unit at the Royal Children's Hospital, Melbourne (Clarke, Andrews, & Austin, 1999). It includes a description of a successful working model with the aim of providing information to allow others to benefit. The scheme has helped many Aboriginal families cope with their fears of using hospitals and assisted in building a bridge between the culture of a mainstream institution and the diverse cultures of Aboriginal families, particularly those from rural and remote parts of the country.

It is likely that there are many more examples of achievements in increasing the accessibility, including appropriateness, of mainstream services to Indigenous people, but either these achievements have never been written up or the reports have not been distributed widely.

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5.3 Indigenous health work force

Background

The important role of Indigenous health professionals in the delivery of services to communities has been recognised for many years, but only in recent years have there been concerted efforts to monitor progress in the development of the Indigenous workforce (National Health Information Management Group NHIMG, 2000). The related measures in the recent revision of the national performance indicators are:

- Indicator 5.1 Number of Aboriginal and Torres Strait Islander peoples who (a) have graduated in the previous year; and (b) are training in key health-related fields.[18]
- Indicator 5.2 Number and proportion of Aboriginal Health Workers who graduated in the previous year or are participating in accredited training.
- Indicator 5.5 Number of Aboriginal identified positions in the health sector.
- Indicator 5.6 Proportion of doctors and nurses who identify as Aboriginal and/or Torres Strait Islander (Cooperative Research Centre for Aboriginal & Tropical Health, 2000).

The most recent data available on these performance indicators are those included in the national summary of the 1998 jurisdictional reports (National Health Information Management Group NHIMG, 2000). There were 784 Indigenous people enrolled in key health-related fields nationally in 1997, a small decline from the 840 enrolments in 1996. In 1997, 158 Indigenous people graduated from health-related tertiary courses in Australia. The courses included dentistry, nursing, pharmacy, podiatry, optometry, medicine, physiotherapy, medical science, pathology and rehabilitation. In terms of specific courses, the number of Indigenous students commencing nursing declined by 32% (from 132 to 90) between 1995 and 1997 (Schwab & Anderson, 1998). The number of commencing students in medicine doubled between 1995 and 1997 (from 6 to 12), but only one Indigenous student commenced study in dentistry in 1997.

In contrast to the decline between 1996 and 1997 in tertiary enrolments, participation by Indigenous people in vocational training (such as through TAFEs) increased (National Health Information Management Group NHIMG, 2000). There were 4,332 Indigenous people studying vocational health courses in 1997, an increase of 726 over the previous year. In 1997, a total of 810 Aboriginal and Torres Strait Islander people in Australia completed

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[18] Key health-related fields are defined as those included in the tertiary training database maintained by the Commonwealth Department of Education, Science and Training (DEST).

vocational training courses, in areas such as health science, dental science, rehabilitation and community care.

Information about Aboriginal (and Torres Strait Islander) Health Worker (AHW)[19] training comes from a variety of sources (National Health Information Management Group NHIMG, 2000). First, the Commonwealth Department of Education, Science and Training (DEST) collates data nationally. Second, the States and Territory health authorities collect some data. Third, the National Centre for Vocational Education Research (NCVER) began collecting in 1997 statistics about Aboriginal and Torres Strait Islander people enrolled in accredited VET sector AHW courses. With three separate sources of data, there are likely to be inconsistencies in the numbers reported.

DEST figures reveal that 145 people graduated nationally as Aboriginal Health Workers in 1997, and 679 people participated in AHW training (National Health Information Management Group NHIMG, 2000). These Australia-wide figures were calculated from publicly funded institutions only. The numbers are less than the sum of those reported separately by some States and the NT, but it is possible that the latter figures may include data from privately funded training bodies. NCVER figures reveal that there were 856 Aboriginal and Torres Strait Islander people (358 males and 498 females) enrolled in accredited VET sector AHW courses in 1997. (Statistics for Western Australia and Tasmania were not collected by NCVER because of variances in the ways those States currently collect enrolment statistics in the VET sector.)

Recent developments

In its inquiry into Indigenous health, the House of Representatives Standing Committee on Family and Community Affairs directed considerable attention to health workforce issues – both Indigenous and non-Indigenous health professionals[20] (House of Representatives Standing Committee on Family and Community Affairs, 2000). The two relevant recommendations are:

Recommendation 26

The Commonwealth, in conjunction with States, Territories and the community-controlled sector, develop within the next two years a national system of training for Aboriginal Health Workers (AHW), which is based on agreed national standards and competencies, and takes into account the varied nature of the roles of AHW. The national system must incorporate a combination of:

- basic local training, based in community-controlled organisations and involving practical work within the community;
- block-release type training, leading to more advanced qualifications, through accredited training organisations, including the AMSs; and
- more formal undergraduate and postgraduate training through TAFE and University.

That the development of a national training system also be supported by the introduction of common classifications for AHW, and an agreed career structure.

Recommendation 32

The Commonwealth ensures that:

- Abstudy/Austudy arrangements are flexible enough to take into account students' differing educational experiences and that Indigenous students are not disadvantaged, either in terms of the level of financial support or time required for completion of degrees, because they have taken a different path to learning; and
- the eligibility criteria are amended to ensure that medical students who agree to scholarships from the Commonwealth or State and Territory health authorities, in return

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[19] Indigenous health workers include both Australian Aboriginal and Torres Strait Islander people, but the term used generally is Aboriginal Health Worker (AHW).

[20] The scope of this review did not permit an analysis of issues related to the non-Indigenous workforce, so attention will be directed here to the Indigenous workforce.

for an agreed period of work in remote or rural communities, continue to be eligible for the full Abstudy/Austudy allowances.

Aboriginal and Torres Strait Islander Health Workforce Draft National Strategic Framework

The general aim of this draft framework, released in November 2001 for national consultation, is to transform the workforce in Indigenous health 'to provide the best possible health system response' (Office for Aboriginal and Torres Strait Islander Health, 2001). The specific objectives include:

- substantially increasing the number of Aboriginal and Torres Strait Islander people working across all the health professions so that there is no longer a racial divide in the health workforce;
- improving the clarity, regulation and recognition of Aboriginal and Torres Strait Islander health workers as a component of the workforce and support for training Aboriginal health workers from within the Vocational Education and Training sector;
- improving the effectiveness of training, recruitment and retention measures targeting non-Indigenous health staff to Indigenous primary health services;
- addressing the range of workforce groups that have not been significantly addressed by previous strategies that have focussed on Indigenous health workers and doctors. These include public health professionals, nurses, dentists, and allied health staff, and the role of the specialist medical workforce and health service management; and
- including clear accountability for government programs to quantify and achieve these objectives and support for Aboriginal and Torres Strait Islander organisations and people to drive the process.

Achievements

There have been a number of significant achievements documented in the literature about the Indigenous health workforce, even though, as with other areas, the literature provides only a partial view of the full extent of these achievements. It is likely also, in view of recent developments (particularly the release of the draft strategic framework for national Indigenous health workforce (Office for Aboriginal and Torres Strait Islander Health, 2001)), that rate of progress in this area will increase in the near future.

Aboriginal Health Workers

AHWs are held in high regard within their community and can have a great impact on the health of Indigenous people. The responsibilities of AHWs include: screening and assessment of patients; referrals; equipment maintenance and interpretation. AHWs also need: to liaise with community members and medical professionals; have knowledge of Indigenous cultural and community issues; have an understanding of traditional and western medical practices; and have the ability to develop and implement health programs (Pacza, Steele, & Tennant, 2001). Great improvements on the health status of Indigenous people can be further achieved by the increased training of skilled Indigenous health workers (Aboriginal and Islander Health Worker Journal, 2000).

The recognition of the valuable contribution that AHWs make to improving the health of Australia's Indigenous population has seen the development of a number of specific training courses for AHWs. Many of these courses and training programs have been designed to address specific health issues. The published literature indicates that programs that have been initiated in collaboration with local Indigenous communities and groups, and which address the needs of a community as identified by the people of the community, have been implemented with great success.

The literature suggests that programs incorporating a 'hands-on' approach provide a valuable learning experience while developing skills in an appropriate manner. It has been noted also that programs and training courses were well received by participants when the course content was culturally appropriate and presented in 'Aboriginal ways' with relevant examples (Busch, 1998). Other health sectors have endeavoured also to provide opportunities for Indigenous people to develop and increase their skills in a variety of ways.

The successful Victorian Aboriginal Health Worker Forum, entitled *Strengthening Aboriginal Health Workers*, allowed many Aboriginal Health Workers to come together in 1998 to discuss relevant issues to their roles (Adams, 1999). The outcomes of this conference, together with a number of other studies, were used to inform Victorian Aboriginal Community Controlled Health Organisation (VACCHO) members about issues related to the development of Aboriginal Health Worker training and to assist them to make informed decisions about the future directions of training in Victoria. This was seen an a vital step in addressing the need for the establishment of accessible and appropriate Aboriginal Health Worker training in Victoria and that this training should be based on the National Competency Standards for Aboriginal and Torres Strait Islander Health Workers.

With advancing technology, more opportunities are becoming available for AHWs in remote areas to increase their skills. The Kimberley Aboriginal Medical Services Council (KAMSC) School of Health Studies Multi Media Office in Broome, WA was responsible for producing a CD-ROM to assist in the training of AHWs, based on the Certificate in Aboriginal Health Work (Aboriginal Communities) AQF 3. The Certificate was developed by KAMSC in Broome, Ngaanyatjarra Health Services in Alice Springs and Marr Mooditj Aboriginal Foundation in Perth (Aboriginal and Islander Health Worker Journal, 1998). The CD-ROM included story-boarding, text authoring and computer programming, and was accompanied by a book. The CD-ROM consisted of six modules – maternal health, child health, primary health care, environmental health, health assessment and Indigenous history – which make up the Certificate and are the basic skills required of an AHW.

The inception of the Australian Indigenous Health Promotion Network has also been seen as instrumental in the health advancement of Indigenous people (Angus, 1997). Through its members – made up of Aboriginal and Torres Strait Islander Health Workers – the network has: contributed to the development of a strong Aboriginal and Torres Strait Islander presence at National Health Promotion Conferences; collaborated with the National Centre for Health Promotion and the Koori Centre at The University of Sydney to develop a graduate Diploma in Indigenous Health Promotion; convened a national symposium on promoting the health of Indigenous Australians; contributed to a major review of infrastructure support for Aboriginal and Torres Strait Islander health advancement; and contributed case studies of programs that have been effective in promoting the health of Aboriginal people and Torres Strait Islander people.

The NT Health Promotion Units, and their training program, have contributed also to an increase in health promotion activity (King & Smith, 1998). The Aboriginal Health Promotion Principles and Practices Training program allows an increased number of community workers and AHWs to participate in training through a hands-on learning experience. The Incentive Fund of the program then allows the worker to use their knowledge and offers funds to support health promotion activities at a community level.

The Charles Sturt University and the Rural and Remote Health Training Unit have been instrumental in improving the nutritional knowledge and skills of AHWs through their accredited nutrition training (Busch, 1998). This program, which targets AHWs, aims to strengthen the partnership between AHWs and nutritionists, and develop culturally appropriate nutrition resources.

It is well understood that diabetes is a costly and serious health problem in the Indigenous community and is a major cause of morbidity and mortality. It has been suggested that the AHW is in the best position to teach Indigenous clients how to manage their diabetes (King & Smith, 1998). To do so, it is important that the AHW receives specialised training. An evaluation, from an AHW perspective, of the Flinders University Diabetes Educators Course was instrumental in bringing about some changes to the course to ensure that it was more appropriate. AHWs who participated in the evaluation agreed that the course content was useful to their work and important to assisting their clients to effectively manage their condition. It was reported also that the course provided an opportunity for both Indigenous and non-Indigenous health professionals to study together and to learn how they could work together to improve the diabetic status of Indigenous people. This also provided an opportunity to establish valuable networks for future use. It was noted that, at the time of the report, the South Australian Aboriginal Partnership had funded 20 AHWs to undertake the DEC training over a two-year period (King & Smith, 1998).

When reviewing training for AHWs in eye health, it was pointed out that the training, career structures, roles and responsibilities vary widely across the country (Taylor, 1997). In some cases, AHWs were well integrated into the health care team, in others their roles were less clear. Some had administrative and managerial responsibilities, for which they may have not received training, and others may have been expected to work beyond their clinical competency (and so be set up for failure and exposure to criticism). Others had developed specialist skills, but had not received recognition for them, or were transferred to areas where the skills were not useful.

Nurses

A number of universities, including the University of Queensland, James Cook University, Deakin University and the Royal Melbourne Institute of Technology (RMIT), have developed programs to increase the number of nursing graduates (Office for Aboriginal and Torres Strait Islander Health, 2001). Other initiatives include strategies for bridging options at the enrolled nurse level, with a view to transition through to registered nursing. In Victoria, The Institute of Koori Education and the School of Nursing at Deakin University are developing a course specifically targeting Indigenous nursing students.

The establishment in 1997 of the Congress of Aboriginal and Torres Strait Islander Nurses (CATSIN) is likely to contribute also to the development of the Indigenous nursing workforce, and improvements in the training of non-Indigenous nurses. CATSIN was formed following a national forum examining strategies to increase the numbers of Indigenous people in nursing (Congress of Aboriginal and Torres Strait Islander Nurses, 1999).

Doctors

In parallel with the establishment of CATSIN, a group of Indigenous doctors set up the Australian Indigenous Doctors Association (AIDA) (Australian Indigenous Doctors Association, 2001). AIDA, which was formed primarily as a support group for undergraduates and to encourage more Indigenous people into the medical field, has a membership of 41 doctors and 60 medical undergraduates currently.

The establishment of AIDA reflects the increasing numbers of doctors, around half of whom have graduated from specifically resourced program at the University of Newcastle (Office for Aboriginal and Torres Strait Islander Health, 2001). The University of Western Australia has a similar program of support for Indigenous medical (and dental) undergraduates.

In terms of advanced training for Indigenous doctors, the OATSIH funded a study tour of New Zealand by the first Indigenous doctor to be admitted to Fellowship of the Australasian Faculty of Public Health Medicine (AFPHM) (Australasian Faculty of Public Health Medicine, 2001). The study tour examined the recruitment of Indigenous doctors to public health medicine in New Zealand. As a follow-up to the study tour, the Indigenous Fellow has been coopted on to the Faculty Council to assist in the development of the Faculty's strategy to encourage Australian Indigenous doctors to train in public health medicine.

Health service managers

The Australian Aboriginal Trainee Health Service Management Program has been implemented to foster management opportunities for Indigenous personnel in all areas of health services (Courtney et al., 2000). Programs such as this aim to increase the number of Indigenous people in middle to senior management positions. In doing so, there is increased accessibility and cultural awareness of the mainstream health system to Aboriginal communities and improved networks and relationships between community-controlled Aboriginal medical services and mainstream health services, together with a greater understanding of the health needs of the Australian Indigenous population.

In an effort to improve the recruitment, retention and professional development of Aboriginal and Torres Strait Islander managers in the health sector, the role of Indigenous people in middle to senior level management positions has been examined (Wakerman, Matthews, Hill, & Gibson, 2000). Forty-one middle and senior level Indigenous health managers expressed high levels of personal motivation to assist Indigenous communities, and the achievement of positive social, economic, political and health outcomes for Indigenous people was a common concern. Government sector Indigenous managers saw themselves as 'agents of change' within the system and Aboriginal community-controlled sector managers engaged in strong community and political leadership roles. The results of this study should improve the recruitment and development of Indigenous health managers at all levels.

Other Indigenous health professionals

The Master of Applied Epidemiology (Indigenous Health) program at the Australian National University is providing opportunities for public health and research training for Indigenous people (National Centre for Epidemiology and Population Health, 2000). James Cook University's School of Public Health and Tropical Medicine, which provides population health courses with a special focus on Indigenous issues (James Cook University, 2002), has produced a considerable number of Indigenous graduates. It is likely also that a number of Indigenous people have graduated from Master of Public Health and similar courses at other universities.

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5.4 Knowledge and information

Health information systems

Background

The need for health information about Aboriginal and Torres Strait Islander people has been recognised since at least 1955 when the National Health and Medical Research Council drew attention to the fact that despite Indigenous mortality and morbidity in parts of Australia being:

> so high as to attract official attention from time to time, no precise information is available to indicate the extent or even the nature of the diseases concerned and no satisfactory means exist for studying their incidence for readily undertaking appropriate measures (NHMRC 1955, cited in Smith, 1978).

It was not until 1984, however, that the Commonwealth established a high-level task force to work with the States and Territories to improve the identification of Indigenous people in health-related data collections (Task Force on Aboriginal Health Statistics, 1985). After a series of meetings with authorities in most States and Territories, priority was given to the development of Indigenous identification in four collections – the births and deaths registration systems and the maternal/perinatal and hospital in-patient collections.

Some States and Territories moved quite quickly to implement the agreements reached with the Task Force, but generally progress was slow. Data of reasonable quality started to become available from some States (WA and SA) and the NT, but it was not until the need of Indigenous health statistics was incorporated within the framework of the National Health Information Agreement that further development was ensured (English, 1995).

In parallel with these developments in health-related information, the ABS was directing more attention to improving the accuracy of Aboriginal and Torres Strait Islander population figures (Barnes, White, & Ross, 1997; Ross, 1999), essential for derivation of health indicators (such as disease prevalence and death rates). This attention included some refinements about the question on Indigenous status, a focus on the census collection procedures, and improvements in editing procedures. These factors have undoubtedly contributed to better enumeration of the Indigenous population over the past 20 years. Other factors, including the greater propensity of Indigenous people to self-identify in censuses, have been seen as more influential, however, in the substantial increase in the Indigenous enumeration between the 1991 and 1996 censuses (Ross, 1999).

The development and reporting of the health-related collections was greatly assisted with the provision of substantial funds by the Commonwealth Department of Human Services and Health to the AIHW to operate an Aboriginal and Torres Strait Islander Health and Welfare Information and Statistics Project (Australian Institute of Health and Welfare, 1996). The Institute contracted the ABS to undertake the work of the project, and the funds enabled the Darwin-based ABS Aboriginal Statistics Unit to be expanded in July 1995 to become the National Centre for Aboriginal and Torres Strait Islander Statistics.

Recent achievements

The Commonwealth decision to provide substantial funds to develop Aboriginal and Torres Strait Islander health information accelerated the progress that had been made since the mid 1980s. An important expression of this progress was the endorsement by the Australian Health Ministers' Advisory Council (AHMAC) in October 1997 of a national plan for Aboriginal and Torres Strait Islander health information (Aboriginal and Torres Strait Islander Health and Welfare Information Unit, 1997). The National Health Information Management Group (NHIMG) was given the responsibility of overseeing implementation of the plan, which included 42 recommendations for the collection and maintenance of quality statistics on the health of Indigenous Australians.

In anticipation of the plan's review in 2002, the ABS and AIHW are working with relevant agencies and other key stakeholders (including representatives of the Aboriginal and Torres Strait Islander community) on a range of activities including:

- six-yearly Indigenous social surveys (to be conducted first in 2002);
- the inclusion of a supplementary Indigenous sample in the National Health Survey (the first sample was included in the 2001 cycle of this survey);
- regular identification of Indigenous people in the Labour Force Survey;
- improved identification of Indigenous people in administrative datasets;
- improving the quality of Indigenous data from the five-yearly Census of Population and Housing and for annual Indigenous population estimates and projections (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

Achievements based on the increased attention include:

- population estimates – improved procedures in recent censuses have produced much better estimates of the Indigenous population.[21] Recently, the ABS has combined information collected by the census with data on Indigenous births, deaths and migration to produce, for the first time, 'experimental' estimates and projections of the Indigenous population by age, sex and State/Territory (Australian Bureau of Statistics, 1998a; Australian Bureau of Statistics, 1998b);
- births data – progress in improving the coverage of Indigenous births has meant that ABS was able to publish information about births registered as Indigenous in 1999 for all States and the NT (the small number registered as Indigenous in the ACT precluded publication for that Territory) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001);
- deaths data – the proportions of Indigenous people correctly identified as such in the death registration systems have been increasing steadily, albeit slowly, over recent years (Australian Bureau of Statistics, 2001; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). It is likely that around 60% of Indigenous deaths overall were correctly identified in 2000, but the proportions were more than 60% only for WA, SA and the NT (Australian Bureau of Statistics, 2001). As well as these jurisdictions, the ABS considered the coverage sufficiently high in New South Wales, Victoria and Queensland for their details to be published also (Australian Bureau of Statistics, 2001);

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[21] There was a 33% increase between the 1991 and 1996 censuses in the numbers of people identifying as Indigenous. Approximately 2% of the total population identified themselves as Indigenous in the 1996 Census.

- hospitals separation data – progress in this area is less certain, and it is likely that only the data for WA, SA and the NT are reasonably complete (Australian Bureau of Statistics, 2001). Data quality audits and special training programs were planned for completion by the end of 2001 in most jurisdictions;[22] and
- perinatal collections – with the exception of SA and Tasmania, the numbers of mothers identified as Indigenous mothers in the State and Territory maternal/perinatal collections were broadly consistent with the numbers projected by the ABS.

Another achievement related to Indigenous health information is its increasing public availability. Since 1997, the ABS's National Centre for Aboriginal and Torres Strait Islander Statistics has published comprehensive reports on Indigenous health and welfare on a biennial basis (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 1997; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 1999; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001), with the AIHW publishing some information in the alternate years (Australian Institute of Health and Welfare, 1998; Australian Institute of Health and Welfare, 2000). Also, as noted above, the annual ABS publications on births and deaths have included Indigenous details in recent years.

Research

Background

In 1989 the National Aboriginal Health Strategy Working Party concluded that 'there exists a large number of Aboriginal health problems which will require a significant research effort' and called on the National Health and Medical Research Council (NHMRC) to 'annually set aside a fixed proportion of research monies it administers for research projects in Aboriginal health' (National Aboriginal Health Strategy Working Party, 1989, p.212). In addition, the Working Party recommended that the Commonwealth allocate $2 million per annum for 'research projects conducted by, and specific to, Aboriginal communities and Aboriginal community-controlled organisations' (National Aboriginal Health Strategy Working Party, 1989, p.212).

Partly in response to the call from the Working Party, the NHMRC acknowledged at its 110th Council Session that one of the great needs in the health and medical research in Australia was in the area of Indigenous health and agreed to make specific funds available (Donbavand, 1991). After discussions between NHMRC and ATSIC, which at that time was the Commonwealth body with responsibility for Indigenous health, it was decided to document existing Indigenous health research as a first step towards setting priority areas for research. The documentation of the research was completed in December 1991 (Donbavand, 1991), but it is not clear what action, if any, resulted.

In 1995, the NHMRC identified 'inequalities in health status, particularly of Aboriginal and Torres Strait Islander people' as one its priority areas, and reported that 0.43% of the research funds allocated for that year had been for Indigenous health research (National Health and Medical Research Council, 1995, p.vii). The NHMRC noted that special funding had been made available in 1995 for Indigenous communities, 'who are being encouraged to ask their own research questions while networks of established scientists are putting these communities in touch with people who can assist them in designing and carrying out appropriate studies' (National Health and Medical Research Council, 1995). This special funding was provided from a special Strategic Reserve Fund (established in 1995), and the Indigenous health

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[22] AHMAC has targeted the improvement of Indigenous identification in hospitals in all States and Territories. This has included assessing the completeness of recording Indigenous status in hospital data collections; implementing or planning training programs for staff; conducting data quality audits; awareness raising for the general public and data collectors; and the documentation of best practice procedures (including less threatening strategies) (Australian Bureau of Statistics, & Australian Institute of Health and Welfare, 2001).

research priority area was managed by a working party 'representative of the communities themselves' as well as the three key NHMRC committees[23].

In its Strategic Plan for the 1997-2000 triennium, the NHMRC emphasised a 'determination to work with OATSIH and others in the interests of Aboriginal and Torres Strait Islander health' (National Health and Medical Research Council, 1997. p.i). There was no specific mention of Indigenous health research within the objectives of the Research Committee (NHMRC's principal research committee), and responsibility for Indigenous research appears to have been given mainly to the Strategic Research Development Committee (SRDC), which had been established to oversee the development and implementation of a program of commissioned research. As part of its work in the development and updating of guidelines and strategies in areas of identified priorities, and the dissemination of information and advice, the National Health Advisory Committee would collaborate with the OATSIH 'with respect to the continuing priority of the health of Aboriginals and Torres Strait Islanders' (National Health and Medical Research Council, 1997, p.11).

A major review of health and medical research in Australia, conducted in 1998-1999, called for greater emphasis on strategic research in areas such as Indigenous health (Health and Medical Research Strategic Review, 1999). As well as seeing enhanced research as 'an important contributor to addressing the gross disadvantage in health status experienced by Indigenous Australians', the Review recognised that the 'participation and leadership by Indigenous people in health research is an important requirement for this research to be effective in providing solutions to health problems' (Health and Medical Research Strategic Review, 1999).

Achievements

The increasing awareness over the past decade of the need for Indigenous health research could be seen as an achievement in itself, but recent developments within the NHMRC suggest that this awareness is just the beginning.

As noted above, main responsibility for Indigenous health research within NHMRC resides with the SRDC, which, in a joint initiative with the OATSIH, established in 1998 an Aboriginal and Torres Strait Islander Health Research Agenda Working Group (RAWG) (National Health and Medical Research Council, 1998). In its first year of operation, the RAWG undertook the following projects as part of the process of developing a strategic research capacity in Aboriginal and Torres Strait Islander health:

- a preliminary analysis of the Aboriginal and Torres Strait Islander health research jointly funded by OATSIH and the NHMRC;
- the development of a methodology for strategic research; and
- piloting of the methodology in the priority area of otitis media (ear infection).

Subsequently, RAWG has commissioned six research projects into diabetes and related disorders in the Indigenous population (Commonwealth Department of Health and Aged Care, 2001a). These projects meet the Indigenous health research criteria of being relevant to a community context, involving the active participation of the community, being planned for sustainability within the community once researchers have withdrawn, and working on interventions that are transferable to other communities.

As well, the NMHRC currently funds 44 other Indigenous health research projects (Commonwealth Department of Health and Aged Care, 2001a), including:

- community-based interventions to reduce the risk of diabetes and cardiovascular disease in Indigenous Australians;
- improving medical services for rural and remote Aboriginal children with chronic suppurative otitis media; and

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[23] At that time, the committees were the National Health Advisory Committee, the Public Health Research and Development Committee and the Medical Research Committee.

- an on-site test for the bacteriological quality of drinking water in remote Aboriginal communities.

Progress within the NHMRC is one indication of achievements in Indigenous health research. Another indication is the numbers of articles published in peer-reviewed journals. Analysis of the Aboriginal and Torres Strait Islander Health Bibliography (Australian Indigenous Health*InfoNet*, 2002) suggests that the average number of peer-reviewed publications increased from 157 per year in the three-year period 1989-1991 to 195 per year for 1998-2000.

It is likely, however, that the average annual number of peer-reviewed articles is an under-estimate of the actual growth in research, partly reflecting the pronounced move to more applied research. Much of this research is disseminated in forms other than peer-reviewed journals. A good example is the increasing number of reports being published by Indigenous-governed research organisations like the Cooperative Research Centre in Aboriginal and Tropical Health (CRCATH) and the VicHealth Koori Health Research and Community Development Unit (VKHRCDU).

Another indication of the growth in the area comes from the number of groups with considerable involvement in the area. As well CRCATH and VKHRCDU, other important centres are, in alphabetical order, the Centre for Remote Health in Alice Springs, the Combined Universities Centre for Rural Health at Geraldton (WA), the Indigenous Australian Research Program of the National Drug Research Institute, Curtin University of Technology in Perth, the Indigenous Health Program at the University of Queensland in Brisbane, the James Cook University of North Queensland at Townsville, Cairns and Mt Isa, the Menzies School of Health Research in Darwin, the National Centre for Epidemiology and Population Health at the Australian National University in Canberra, the South Australian Centre for Rural and Remote Health at Whyalla, the TVW Telethon Institute of Child Health Research in Perth, and Yooroang Garang, the School of Indigenous Health Studies at the University of Sydney.

Ethics in research and information

Background

The major concerns expressed by the 1989 National Aboriginal Health Strategy Working Party on the ethical aspects of Indigenous health research (National Aboriginal Health Strategy Working Party, 1989) were echoed in background information to *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, endorsed by the NHMRC in 1991 (National Health and Medical Research Council, 1991). This background information reviewed changing perceptions in Indigenous health research and outlined the need for special consideration of ethics. It was noted that research had generally been more concerned with matters of interest to science or to non-Indigenous researchers than to Indigenous people and communities, and had often been insensitive to the values, needs and customs of Indigenous communities. The lack of appreciation of ethical issues had led to lesser standards in research for Indigenous people than for other Australians concerning, in particular, community consultation and negotiations, community views, informed consent, and access to sensitive areas. Indigenous people were seen also as more vulnerable than non-Indigenous people were to exploitation by persons conducting research.

Achievements

Since the promulgation of the NHMRC guidelines, substantial progress has been made in their incorporation into the processes of institutional ethics committees (IECs) across the country. An example is the AIHW Ethics Committee (Australian Institute of Health and Welfare, n.d.).

In addition, Indigenous-specific ethics committees have been set up in a number of States and Territories. Examples are the Western Australian Aboriginal Health Information and Ethics

Committee (WAAHIEC), which is appointed by the Minister for Health and chaired by an Indigenous person nominated by WAACCHO (Western Australian Aboriginal Community Controlled Health Organisation) and appointed by the Minister for Health (Office of Aboriginal Health, 2002), and the Ethics Committee of the Aboriginal Health and Medical Research Council of New South Wales. Another example is the Aboriginal Health Service Health Research Ethics Committee in Melbourne (VicHealth Koori Health Research and Community Development Unit, 2000). The committee determines whether research is likely to be appropriate and acceptable to the local Indigenous community, and may seek changes before endorsing or rejecting applications.

An update of the NHMRC guidelines has been scheduled for some time, and was set as one of the 'immediate priorities' in the Council's strategic plan for 2000-2003 (National Health and Medical Research Council, 2000, p.12). The NHMRC already requires applicants for Project Grants in the area of Indigenous health research to address special Indigenous Health Research Criteria (National Health and Medical Research Council, 2001). In addition to criteria of community participation, sustainability and transferability, there is also an emphasis on priority-setting capacity. Researchers are required to demonstrate to what degree their research question is a community-identified priority – if not, then it is suggested that the research is not a priority and to pursue the matter would be inappropriate.

Parallel to the NHMRC guidelines are ones developed by Australian Institute of Aboriginal and Torres Strait Islander Studies, primarily for research sponsored by that Institute (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2000). These guidelines stress that it is essential that Indigenous participants in any research project should achieve a shared understanding of the aims and methods of the research and share the results of the work in a form that is useful and accessible. Principles revolve around consultation and negotiation in a two-way process with an honest exchange of information about aims, methods and potential outcomes. Research should be beneficial to Indigenous people at a local level (with an obligation for the researcher to give something back to the community), and more generally.

As well as these types of guidelines for research, attention has been directed also to guidelines for the use of health information collected as part of administrative data collections (such as the births and deaths registration systems and the hospitalisation collections maintained by State and Territory health authorities). An example is the NSW Aboriginal Health Information Guidelines, which were developed 'to ensure consistency and good practice in the management of health and health-related information about Indigenous people in NSW' (Aboriginal Health Information Management Group (New South Wales), 1998, p.1). The guidelines provide a framework and set of principles for the collection, ownership and use of information, as well as addressing issues of confidentiality and privacy.

As well as the development and implementation of ethical guidelines for Indigenous health research and information, some work has examined specific aspects of ethics and research. For example, the Centre for Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) in Darwin has explored Indigenous values and priorities in *Research partnerships: yarning about research with Indigenous peoples* (Franks, 2001). The CRCATH has also studied the links between health research and policy, services and consumers (Matthews, Jenkin, Frommer, Tjhin, & Rubin, 2001).

Another example is the work in Victoria of the VicHealth Koori Health Research and Community Development Unit (VKHRCDU), which is committed to undertaking, collaborating in and supporting research to benefit the Koori community (VicHealth Koori Health Research and Community Development Unit, 2001). In its discussion paper *Indigenous health and 'Western Research'* (Humphery, 2000), details of ethical guidelines, the resulting rhetoric and the reality at grass roots level are combined in a comprehensive overview. In presenting Indigenous critiques of research practice, the paper identifies four main areas of contention: the past exploitative and disrespectful treatment of Indigenous people in research; the power of the research process in the hands of non-Indigenous researchers and research organisations; non-delivery of benefits to Indigenous people; and misrepresentation of Indigenous societies, cultures and individuals. It notes that research involving Indigenous people is now a more complex and restrictive process, in which researchers need to reflect on their own suppositions, action and motivations. Another positive outcome is Indigenous self-determination in research, with increasing numbers of Indigenous people undertaking research themselves and also enforcing the principle of Indigenous control.

Knowledge management

Background

Effective knowledge management is being recognised increasingly as critically important as organisations – private and public – attempt to address the economic, social, and technological changes that have taken place over the past decade or so (Knowledge Management Working Group. Federal Chief Information Officers Council, 2001).

In general, knowledge management (KM) involves three major components – people, processes and technology – and seeks to apply the collective knowledge and abilities of the entire work force to achieve objectives (Knowledge Management Working Group. Federal Chief Information Officers Council, 2001). The concept recognises the differences between data (unorganised facts), information (data plus specific context) and knowledge (information plus judgement). KM focuses on people and organisational culture to stimulate and nurture the sharing and use of knowledge; on processes or methods to find, create, capture and share knowledge; and on technology to store and make knowledge accessible and to allow people to work together without being together.

An aspect of KM justifying special mention is the area of research which attempts to make the findings of pure and applied research available in a form that facilitates their translation into action. Knowledge translation is the term used by the Canadian Institutes of Health Research (CIHR)[24] for this branch of research (Canadian Institutes of Health Research, 2002). Knowledge translation (KT), which involves a complex set of interactions between producers of new information and its translation into knowledge for potential users, moves beyond reliance on academic publication as a primary mechanism for disseminating results.

Systematic reviews of individual health interventions and other topics, such as those undertaken by the Cochrane Collaboration, represent specific examples of KT for a particular audience (clinical health service providers). The Australian Institute of Heath and Welfare (AIHW) also undertakes some KT, as does Health*Insite* for health consumers (HealthInsite, 2001). There are no systematic approaches, however, to address the needs of other potential users of knowledge (such as policy makers, students and the general community).

Achievements

The last decade has witnessed substantial progress in the sharing of information and knowledge about Indigenous health. As noted above, the ABS's National Centre for Aboriginal and Torres Strait Islander Statistics has published comprehensive reports on Indigenous health and welfare on a biennial basis since 1997 (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 1997; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 1999; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001), with the AIHW publishing some information in the alternate years (Australian Institute of Health and Welfare, 1998; Australian Institute of Health and Welfare, 2000). As noted above also, the annual ABS publications on births and deaths have included Indigenous details in recent years.

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[24] The Canadian Institutes of Health Research is the Canadian Government agency responsible for funding and fostering health research in Canada. In this area, it is the Canadian equivalent of the National Health and Medical Research Council.

These publications have been complemented by reports on specific topics commissioned and published by the OATSIH (see, for example, *Better health care* (Commonwealth Department of Health and Aged Care, 2001b) and *The management of HIV/AIDS* (ANCAHRD, 2000)).

The OATSIH has also commissioned the development of clinical care guidelines for health professionals working in the areas of Indigenous health (see for example, the guidelines for diabetes (Couzos, Metcalf, Murray, & O'Rourke, 1998), otitis media (Menzies School of Health Research, 2001), and cataract, diabetic retinopathy and trachoma (Office for Aboriginal and Torres Strait Islander Health, 2001).

Many other useful publications have been produced by research and other organisations, such as the Menzies School of Health Research and the Cooperative Research Centre for Aboriginal and Tropical Health. Recent examples include: *Evaluation of the specialist outreach service in the Top End of the Northern Territory* (Gruen & Bailie, 2000), *Evaluation of an Aboriginal Empowerment Program* (Tsey & Every, 2000) and *Indigenous Australians and tobacco: a literature review* (Ivers, 2001).

In terms of general information and knowledge needs, Australia is leading the world in its support of the Australian Indigenous Health*InfoNet* (Wooldridge, 2000), which provides a model in how KM and KT can be applied systematically for specific health areas. In attempting to address the knowledge needs of the variety of potential users of Indigenous health knowledge, the Health*InfoNet* researches and develops detailed overviews of specific health topics, introductory material about specific conditions, regularly updated summaries of Indigenous health status, and brief answers to frequently asked questions. Knowledge of these types is complemented by useful information related to specific health areas. The Health*InfoNet*'s knowledge and information is disseminated to users mainly via the Internet (www.healthinfonet.ecu.edu.au).

Effective KM and KT require actions based on knowledge, so the Health*InfoNet* also works directly with Indigenous people to improve their use of the Internet, and assists Indigenous and other relevant agencies in Internet site development – to make their knowledge and information accessible.

Summary

In terms of both KM and KT for Indigenous health, there have been a number of significant achievements over the past decade. Not only has there been much more regular and comprehensive publication of information and knowledge about Indigenous health, but also the publication of reports on specific health topics and of clinical care guidelines. A number of these reports have been disseminated also via the Internet.

The Internet is also the main means of dissemination of knowledge and information by the Australian Indigenous Health*InfoNet*, which has the potential to be a key element in a national knowledge strategy for Indigenous health.

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6 Achievements in specific areas of Indigenous health

6.1 Health risk factors

Physical activity

Background

The 'Active Australia' initiative, launched in 1996, signified the growing recognition in Australia of the importance of physical activity for a healthy life (Commonwealth Department of Health and Family Services, 1998). The Active Australia framework identifies physical activity and increased participation as public health priorities.

The increased focus upon physical activity as a health priority draws on a substantial body of international evidence identifying a sedentary lifestyle as a risk factor for poor health outcomes (U.S. Department of Health and Human Services, 1996). There is also considerable evidence linking physical activity and the prevention of certain chronic diseases.

In the context of this national movement, there is increasing interest in interventions for Indigenous people, but less understanding of the best methods to be employed. Given the high prevalence of chronic diseases (such as coronary heart disease, diabetes and hypertension) in Indigenous communities (Australian Institute of Health and Welfare, 2000), increased physical activity is likely to produce significant health benefits. 'Organised physical activity also potentially facilitates political and community outcomes, which are as significant as the physiological benefits. …. There is also a perception that sport and recreation, or organised physical activity, is a valuable community development tool that will assist with improving Indigenous social and health outcomes' (Cairnduff, 2001, p.1).

With all of these potential benefits of increased physical activity, interventions have steadily increased since 1996. Physical activity programs appear to target two broad areas:

- young Indigenous people, with the objective of increased participation and performance;
- Indigenous women (including a focus upon the barriers experienced by Indigenous women), aiming at improving physical health (for example, obesity and diabetes) and psychological wellbeing (self-esteem, confidence, social connections).

Unfortunately, few physical activity programs for Indigenous people have formalised, regular evaluation processes. The reasons identified for this include:

- under-resourcing of the sector to conduct research and evaluations;
- insufficient skills in the sector to conduct research and evaluations; and,
- insufficient or inappropriate evaluation tools to reflect objectives (Cairnduff, 2001).

Funding bodies, such as ATSIC and the Department of Sport and Recreation, have internal monitoring mechanisms that are used to examine programs. Often these mechanisms rely on financial information and participation rates. They may not adequately reflect the impact or effectiveness of the program. Apart from anecdotal evidence, there appears to be little evaluation of sport and recreation programs.

An evaluation of ATSIC-funded sport and recreation programs conducted by the University of Canberra showed that this issue is faced throughout the sport and recreation sector (University of Canberra, 2000). The study revealed that it was difficult to assess the progress of programs, due to inadequate reporting procedures and inappropriate evaluation tools. Participation rates were found to inadequately reflect all of the objectives that programs are expected to deliver (Cairnduff, 2001).

A number of physical activity programs faced barriers or hurdles, especially at the onset. Successful programs appear to overcome these barriers by being 'embedded' in the community – that is, by having community support behind them. It is likely that a number of programs are less successful than they could be, because they haven't appreciated the importance of community participation in all facets of the development, implementation and evaluation process.

Despite the barriers, the physical activity programs that have been implemented with community involvement and have been evaluated (formally and/or informally) show promising results.

Achievements

As noted above, increased participation of Indigenous people, particularly youth, in sport and recreation is the main objective of programs addressing lack of physical activity as a risk factor for ill health. By increasing participation, programs hope to improve Indigenous social, emotional and physical wellbeing, and achieve greater community capacity (for example, by diverting Indigenous youth away from antisocial behaviour).

The ability to address and overcome the barriers to participation in physical activity experienced by Indigenous people, especially Indigenous women, is a focus of many physical activity programs (for example, WAVES (Cawood, 1999) and the Cherbourg Healthy Lifestyles Program (Thompson et al., 2000)). Assessment of participation rates is one of the easier evaluation methods and gives worthwhile evidence of the performance of a program. Taking this into account, it is thus not surprising that participation rate has been found throughout the literature to be one of the most common and useful performance indicators of physical activity programs.

A 'model program', such as the Cherbourg Healthy Lifestyles Program (Thompson et al., 2000), addresses the high prevalence of being overweight and health problems (including hypertension and diabetes) among local women by improving their health and fitness. To 'get active' for their families and their health and 'to have fun!' were the goals of the women involved and, thus, the informal performance indicator for the program. An evaluation after one year showed that this had been achieved, with more than 120 women and 30 men participating in the fitness classes (approximately 20% of the Cherbourg population) with positive feedback from participants clearly indicating that they had indeed 'gotten active' and 'had fun'.

The Rumbalara Football and Netball Club in Victoria is another example of a successful community physical activity initiative (Potter, 2000). The sporting achievements of club members have played an important role in the community, with the Yorta Yorta people producing many sporting and athletic champions. The Rumbalara Football and Netball Club is much more than a sporting club – it's a vehicle to nurture reconciliation and improve physical, emotional and spiritual wellbeing for the Goulburn Valley's Koori community.

Identifying talented Indigenous athletes and improving their performance through support, coaching, and education initiatives is a popular focus of programs in the area of physical activity (for example, the NT Indigenous Sports Council (Cairnduff, 2001) and the Indigenous Athletes Forum (Turner, 2000)). Increased Indigenous participation rates in the AFL (Australian Football League) is a common example (Rio Tinto AFL Kickstart Program (Cairnduff, 2001)). By increasing the public profile of elite and professional Indigenous athletes, it is hoped that Indigenous people (particularly youth) will be inspired to participate in sport and recreation (for example, Indigenous Women in Sport Summit (Turner, 2000)).

The long-term health benefits were seen to take a 'back seat' to the immediate social and emotional benefits evidenced in physical activity programs. Such benefits are much more apparent through informal evaluation methods and are also more evident in the short-term. The extremely important health benefits (for example, decreased risk of cardiovascular disease) are, of course, important and extremely worthwhile goals of these programs also. As many of these programs are relatively new, however, such evidence is not yet available. Evidence of achievement is thus seen through participation rates, and social and emotional feedback obtained from participants.

Overall, the health benefits of physical activity programs were seen to be:

- improved social wellbeing;
- improved physical health;
- improved self-esteem;
- reduction of weight;
- management and reduction of diabetes and hypertension;
- reduction of cardiovascular disease; and
- a way of having fun.

Summary

The physical activity programs that have been implemented and evaluated show extremely positive results, at least in terms of participation. Physical activity is an area where much physical, emotional and social benefit can be gained simply be increasing participation rates.

Initiatives such as the NT Institute of Sport's support of Indigenous athletes to compete at a regional level (Cairnduff, 2001) reveal the potential of such programs. There is a need, however, for increased assistance to enable well managed physical activity programs and services to Indigenous communities (Cairnduff, 2001).

There is a need also for increased support to improve Indigenous access to sport and recreation facilities Australia-wide (for example, through grants to community councils (Cairnduff, 2001)). The evidence shows the potential of sporting clubs to become a positive focal point of the community (for example, the Rumbalara Football and Netball Club), but action is needed to expand upon, promote and utilise these 'models'.

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Nutrition and obesity

Background

Food is an integral part of our daily lives and eating habits are an important determinant of general wellbeing. It has long been acknowledged that good nutrition is essential to good health, particularly in the prevention of many non-communicable diseases (such as cardiovascular disease, diabetes, some cancers, obesity, gall bladder disease, iron-deficiency anaemia, dental caries, and, more recently recognised, renal disease). The major causes of diet-related mortality and morbidity within the Indigenous population are cardiovascular disease, diabetes and renal disease (National Health and Medical Research Council, 2000).

Food supply and cost

In order to achieve good nutrition and good health, it is essential that an adequate supply of healthy and affordable food is available throughout the life cycle. Social, economic, geographical and environmental factors all influence the availability of healthy and affordable food. Low socioeconomic status and geographical isolation are among the factors that limit the availability of nutritious foods in many Indigenous communities (National Health and Medical Research Council, 2000). This aspect was noted by the House of Representatives Inquiry into Indigenous Health, which recognised the need to improve the availability of fresh fruit, vegetables and meat in remote communities (House of Representatives Standing Committee on Family and Community Affairs, 2000).

The transition in lifestyle and diet

Traditionally, Indigenous people were self-sufficient populations practising gathering and hunting activities for their food supply (National Health and Medical Research Council, 2000). With European settlement, these activities diminished to varying degrees and led, in many instances, to a situation of dependency of Indigenous people on Europeans for food as well as for many other resources. The foods consumed through early European settlement were highly processed to survive long periods of transportation and storage. They were generally high in sugar, fat and salt, and the types of carbohydrates and fat were very different to those found in traditional foods. Today, many foods consumed by Indigenous people in remote areas are nutrient poor and energy dense compared with traditional foods. Foods such as vegetables and fruit, which are high in nutrients, are often of poor quality and expensive, and may not be available at all.

The health consequences of poor nutrition

Food supply and consumption patterns have important implications for nutrition, growth, weight and associated health conditions in the Indigenous population (Cunningham & Mackerras, 1998; National Health and Medical Research Council, 2000). The nutritional profile of Indigenous Australians varies greatly within and between communities, but is frequently inadequate. It is characterised by under- and/or over-nutrition at various stages of the life-cycle.

Maternal malnutrition is not uncommon among Indigenous women and contributes to high levels of intra-uterine growth restriction and low birthweight (National Health and Medical Research Council, 2000). Under-nutrition during infancy and early childhood is higher than in the general population, and a significant number of Indigenous pre-school children from rural and remote areas have an unacceptable level of malnutrition . On the other hand, obesity is increasingly prevalent across age groups and sexes. Higher than expected levels of both underweight and overweight status have been documented among Indigenous children aged 7-15 years (Cunningham & Mackerras, 1998). According to Australian standards, more than one quarter of Indigenous boys and girls may be considered overweight or at risk of being overweight. Survey results show greater numbers of overweight children in urban areas but also a surprisingly high proportion in rural areas. Among adults (18 years and over), 60% of males and 57% of females across all regions are considered overweight or obese (Australian Bureau of Statistics, 1997).

Obesity

Changes in the dietary patterns of many Indigenous people have been accompanied by other lifestyle changes (such as reduced levels of physical activity) and have contributed to high levels of obesity in Indigenous communities. The 1994 National Aboriginal and Torres Strait Islander Survey (NATSIS) found that 25% of Indigenous males aged 18 years or older and 28% of Indigenous females of that age group were obese (body mass index (BMI) of 30 or more), compared with about 19% of all Australian males and females (Cunningham & Mackerras, 1998). Particularly high levels of obesity were found among Torres Strait Islanders, with 43% of adult males and 50% of adult females having a BMI of 30 or more (Cunningham & Mackerras, 1998).

Obesity is closely associated with several of the main causes of Indigenous morbidity and mortality, specifically type 2 diabetes, cardiovascular disease and renal disease. Other complications of obesity include respiratory disorders, gastrointestinal disease, syndrome X and complications of pregnancy (National Health and Medical Research Council, 2000).

Recent initiatives

The need to improve the nutritional status of Indigenous people is reflected in the recent funding of two pilot projects (Commonwealth Department of Health and Aged Care, 2001). One is a community stores project which aims to improve the functioning of stores by stocking fresh food at affordable prices. The second is a collaborative research project based on the manufacture of a prototype kitchen according to the National Indigenous Housing Guide specifications (Aboriginal and Torres Strait Islander Commission, 1999). The kitchen will incorporate state-of-the-art health hardware which allow Indigenous people to prepare, cook and store food in a healthy manner.

Funding for a further 93 community-based projects has been granted under The National Child Nutrition Program. Of these projects, approximately 23% were to Aboriginal and Torres Strait Islander communities with many others incorporating Indigenous communities as priority needs groups (Commonwealth Department of Health and Aged Care, 2001).

Achievements in health outcomes

A number of nutrition programs have been successful in achieving improvements in dietary patterns and/or health outcomes. Some have resulted in increased consumption of fruits, vegetables, wholemeal bread, fruit juices and decreased intake of sugars and carbonated soft drinks (Lee, 1993).

Among the few programs specifically targeting weight loss, a couple have demonstrated positive results. A recent evaluation of Queensland's 'Healthy weight program' demonstrated that the majority of participants who remained on the program for at least 8 weeks lost weight and decreased their waist and hip measurements (Dunn & Dewis, 2001). Aboriginal health workers received training to facilitate community-based weight management workshops and conduct ongoing assessments of participants. Participants indicated that training improved their nutrition skills and knowledge, and that program resources were useful for other aspects of their work (Dunn & Dewis, 2001). The capacity of Indigenous health workers to have a positive impact has been recorded, and recommendations have been made to integrate nutrition skills into workforce development projects (Taylor, 1999).

Another Queensland initiative has had some success facilitating weight loss among Indigenous men (Egger et al., 1999). A version of the 'GutBuster' program, modified by and for men from island communities in the Torres Strait, demonstrated modest reductions in abdominal obesity in the program's first year (average weight loss – 3.3 kg; average waist loss – 4.0 cm; average percentage decrease in fat mass – 10.8%). The project also demonstrated that environmental changes at the structural level (for example, increased supply of fresh fruit, vegetables and low fat foods to stores) may be achieved through cooperation with organisations involved in food distribution (Egger et al., 1999).

General achievements

Numerous nutrition programs implemented within Indigenous communities throughout Australia have had positive effects on nutritional status and have contributed to improvements in other health and community development outcomes. In particular, several programs have achieved high levels of community participation and have been responsible for raising awareness of health issues (such as heart disease and diabetes). Adult participants have come to realise that they can improve their own health by making changes, and, just as importantly, they can encourage their children to adopt a healthier diet to help prevent diseases later in life. These factors were evident in the Looma Diabetes Program which was implemented in the community of Looma (Kimberley, WA) to address the high prevalence of diabetes (Ellis, 1996).

Other programs, such as the health and nutrition project implemented at Minjilang (Croker Island, NT), have worked to realise community power and strengthen community capacity (Lee, 1993). To ensure the availability of fresh produce, the community council arranged a regular air charter to deliver fresh fruit and vegetables and wholemeal bread from a mainland mining town at a time when a non-supportive store manager had been appointed to the community store. This action resulted in the store manager bowing to the communities' demands and restocking the required foods in the store.

Where community stores have supported nutritional initiatives – by stocking a wider variety of healthier foods and using supportive strategies within the stores – sales of such products have increased. Evidence of this was seen in a central Australian community where the food-purchasing behaviour of children and young Aboriginal people was monitored following the implementation of a nutritional intervention (Scrimgeour, Rowse, & Knight, 1994). The intervention used a multi-level approach including: school-based nutritional activities; family group education workshops; a wide variety of foods being maintained in the stores; healthy foods identified and labelled with stickers and placed at eye-level throughout the stores; and confectionary at the point of sale being replaced by fresh fruit. Overall, sales of the foods and drinks which had been discouraged in the intervention had decreased and there was an increase in the sales of the foods and drinks that had been encouraged (Scrimgeour et al., 1994).

A study of four communities in western NSW found that the food consumption habits of residents was influenced by the extent and type of external advertising, food price and availability, and takeaway food outlets (Rodgers, Willis, & Thomas, 1998). These factors need to be considered in the development of nutritional interventions.

Summary

The literature reveals that many programs lack evaluation. It appears also that a large number of projects are implemented and achieve positive results, but that results are not reported and disseminated through the available literature.

Of nutrition programs initiated in communities throughout Australia, many have resulted from the concerns of community members or Indigenous health workers. An important factor in the success of programs appears to be the extent of community participation and leadership. Some programs have integrated traditional Indigenous dietary practices and the knowledge and experience of older community members.

Improved nutrition and reduced levels of obesity are important in addressing the main causes of morbidity and mortality in the Indigenous population (National Health and Medical Research Council, 2000). Efforts to promote healthy lifestyles (such as healthy eating and drinking, regular physical activity and reduced cigarette smoking) should not only help reduce levels of obesity but also minimise the risks from related disorders, such as cardiovascular disease and type 2 diabetes.

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Alcohol

Background

A contributing factor to the poorer health status of Indigenous populations is the high prevalence of alcohol and other drug use in communities (Walley & Sullivan, 1996).

Over recent years, various reports and research findings have demonstrated that while fewer Indigenous than non-Indigenous Australians drink alcohol, those Indigenous people who drink are more likely to do so excessively. The 1995 National Health Survey found that over 20% of Indigenous male drinkers were in the high-risk category for alcohol consumption, compared with 8% of non-Indigenous male drinkers. Indigenous females were less likely to be in the high risk category than Indigenous males, but were still more likely than non-Indigenous women drinkers to be consuming alcohol at hazardous levels (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

The hazardous use of alcohol is related to a number of specific health conditions (including high blood pressure, stroke, some cancers and, specifically, alcohol dependence syndrome and alcoholic liver disease) (Anderson, 1996). Alcohol use is implicated also in a variety of injuries (such as those from motor vehicle accidents, assault and self-harm) (Harrison, Miller, Weeramanthri, Wakerman, & Barnes, 2001), and may contribute to social problems (such as family breakdown, domestic violence, financial and legal problems) (Davis, 1998).

Achievements

A wide array of projects and interventions aimed at reducing levels of consumption and associated harms have been initiated by both Aboriginal community-controlled organisations and government agencies (Gray & Sputore, 1998).

There have been unprecedented changes in the climate of opinion within some Indigenous populations about the use and abuse of alcohol. Effective strategies – such as community- and town-based night patrols, sobering up centres, licensing strategies and lobbying actions by Indigenous people leading to alcohol restrictions – have now become established practice. (Brady, 1997).

Programs and interventions addressing alcohol consumption in Indigenous populations are plentiful, but, as few formal evaluations take place, any conclusions about what works can only be seen as tentative. In spite of the limited number of evaluation reports, several conclusions can be cautiously drawn.

Supply reduction strategies, which restrict the supply of alcohol, appear to have produced the most substantial results (Brady & Martin, 1999; Gray, Saggers, Sputore, & Bourbon, 2000). Restrictions on the provision of cask wines, price increases for alcoholic drinks, lowering the legal limit for drivers, and restrictions on hours of trading for licensed premises, have been positive initiatives (Stockwell et al., 2001). In parallel with these initiatives, the development of a responsible server culture is seen as an important component of supply reduction strategies (Brady & Martin, 1999). Existing programs should be enhanced by targeting sales practices and high-risk consumption patterns, and changes in licenses and hours of sale should be considered (Brady & Martin, 1999). Of course, making alcohol less easily available can be inconvenient for some people. However, there is good international and Australian evidence that controlling physical access to alcohol through various kinds of restrictions does lower the consumption of heavy drinkers, and, thus, lead to fewer alcohol-related problems (Brady & Martin, 1999).

Alcohol consumption is high in the NT, but there have been a range of positive achievements which can be built upon. For example, the NT was the first jurisdiction in Australia to introduce legislation with the objective of reducing harm associated with alcohol consumption (Brady & Martin, 1999). Indigenous organisations have increased their awareness and involvement in alcohol-related issues over the last decade or so, and communities have made use of the 'dry areas' provision in the Liquor Act (Brady & Martin, 1999). The innovative use of an alcohol levy has also been in place since 1992. The proceeds of the levy support increased treatment, public education and other prevention activities, and it is apparent that there has been a substantial reduction in alcohol-related harm in the NT as a result of the alcohol levy and the 'Living with Alcohol' program (Stockwell et al., 2001).

Between September 1988 and February 1989, Anyinginyi Congress, an Aboriginal community-controlled health organisation, facilitated a collaborative community action against striptease shows in public bars in Tennant Creek (NT). This action resulted in alterations to the guidelines of the NT Liquor Licensing Act to regulate striptease shows in public bars, and begun other processes of tackling alcohol-related problems in the community. Territory-wide community collaborative action has had far-reaching effects, including strategies which made people – many of whom were previously unaware of the issues – draw a link between the availability of alcohol and alcohol-related problems, particularly violence and ill-health within the community (Boffa, George, & Tsey, 1994).

Liquor licensing and community action have been found to have a real impact on alcohol consumption and alcohol-related harm. Restrictions on alcohol availability have a modest, but real impact on alcohol consumption and levels of associated harm (d'Abbs & Togni, 2001). Restrictions on availability are a successful means of reducing alcohol-related harm at a local level, and are likely to have a robust sense of community support, providing other measures are also pursued. The Derby Liquor Licensing Trial aimed towards reducing excessive drinking by limiting liquor outlet opening hours and related measures for a 3-6 month trial period. An achievement of the trial was a significant drop (37%) in the incidence of offences in the categories of assaults, sexual offences, damage and threatening behaviour (d'Abbs & Togni, 2001).

Summary

There are several main conclusions to be drawn when considering achievements in the alcohol-related area. Unfortunately, few studies suggest clear directions for policy (Gray & Sputore, 1998). This is seen as the direct result of the lack of evaluation reports. From this review, it is clear that there is a pressing need for more rigorous evaluation studies, in cooperation with Indigenous community organisations.

Community control and participation are essential if effective and culturally appropriate initiatives are to be implemented (Gray & Sputore, 1998). Strengthening and supporting community organisations and developing Indigenous workers' skills are essential in this process, as is the development of partnerships.

There is a need also to employ a broader range of treatment models and complementary intervention strategies. Supply reduction strategies appear to be effective, but there is a pressing need for more meticulous evaluation studies in cooperation with Indigenous community organisations (Gray et al., 2000).

The broader context within which alcohol drinking takes place must be remembered also when focusing on effective alcohol intervention programs. In the interests of both general public health gains and social justice, there is an urgent need to address the fundamental inequalities faced by Indigenous people (Gray et al., 2000).

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Cigarette smoking

Background

Smoking tobacco is a major cause of ill health and mortality, killing about half of all regular cigarette smokers (English et al., 1995a; English et al., 1995b). Smoking increases the risk of cardiovascular disease (coronary heart disease, stroke, atherosclerosis), some cancers (lung, oropharyngeal, laryngeal, bladder, pancreas, cervical), and respiratory disease (chronic obstructive airways disease, pneumonia) (Australian Indigenous Health*InfoNet*, 2001b). Females who smoke during pregnancy increase their risk of ectopic pregnancy, spontaneous abortion (miscarriage), premature birth, low weight of babies at birth, and stillbirth. Smoking is also associated with other conditions such as peptic ulcers, ulcerative colitis, and fire injuries.

Much higher proportions of Indigenous than non-Indigenous people smoke. The 1994 NATSIS (National Aboriginal and Torres Strait Islander Survey) found that 54% of Indigenous males and 46% of Indigenous females aged 13 years or more smoked (Australian Bureau of Statistics, 1994). These levels compare with around 22% of all Australians who smoked at that time.

The proportions of Indigenous Australians who said they smoked varied from region to region, ranging from 39% to 80% for Indigenous males and from 17% to 69% for Indigenous females (Australian Bureau of Statistics, 1994). About 15% of Indigenous males and 14% of Indigenous females aged 13-15 years said they smoked. For Indigenous people aged 22-24 years, over 60% of males and over 50% of females said they smoked.

Smoking-related deaths are much higher for Indigenous people than for non-Indigenous people. Indigenous people are up to 8 times more likely to die from smoking-related diseases than are non-Indigenous people (Cunningham, 1994). The most common cause of death among Indigenous people due to cigarette smoking is coronary heart disease (CHD) (Australian Indigenous Health*InfoNet*, 2001a; Unwin, Gracey, & Thomson, 1995). The next most common cause of death is lung cancer for Indigenous males, and chronic bronchitis for Indigenous females.

Achievements[25]

Smoking cessation strategies for Indigenous Australians have included interventions in primary care, in the community, and in legislation (Ivers, 2001). These strategies have been implemented by a range of organisations, including the Commonwealth, State, Territory and local governments, Indigenous community-controlled health organisations and non-government organisations.

Many Indigenous health professionals are being educated/trained in the health effects of tobacco through institutions such as Batchelor College and Danila Dilba Medical Service's training school, but, overall, the number of Indigenous people trained in tobacco control is

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[25] A recent literature review by Rowena Ivers on tobacco smoking among Indigenous people provides a comprehensive analysis of the subject (Ivers, 2001). This report draws heavily on that review, but doesn't attempt to cover the area in anywhere nearly as much detail.

limited (Ivers, 2001). Participants interviewed in the Australian Medical Association's review of Indigenous tobacco use commented that there was a clear need for tobacco control training in order to maintain a skilled workforce in the area (Australian Medical Association and Australian Pharmaceutical Manufacturer's Association, 2000).

Training health staff about smoking cessation has been shown to have a small but significant effect on increasing the number of smokers who quit in the general population (Ivers, 2001). However, there has been no evaluation of the effect of training health staff working with Indigenous people in giving advice about tobacco.

Training packages

Two training packages for Indigenous health workers were identified – the Gnummari Wa training manual (Marr Mooditj Foundation Incorporated and Health Department of Western Australia, 1995) and the Tobacco book (National Heart Foundation, 1999). Even though these packages have not yet been evaluated, their production and distribution can be viewed as an achievement as the need for such educational resources is indisputable.

The Gnummari Wa training manual, video and other resources about tobacco were developed by the Marr Mooditj Foundation for Indigenous people in WA (Marr Mooditj Foundation Incorporated and Health Department of Western Australia, 1995). Courses were held with assistance from the Health Department of WA to train Indigenous health workers about how to advise smokers to quit.

The Tobacco book was developed by the National Heart Foundation with the Tiwi Health Board and Bagot Community Council, and in consultation with community members of Nguiu, Pirlangimpi, Milikapiti and Bagot (National Heart Foundation, 1999). The book is of use to health professionals in explaining the effects of tobacco and marijuana on the body. Using pictures, the book explains the effects that smoking has on other members of the family and on unborn babies. The book also describes the body's reaction to quitting smoking and gives some strategies.

Community programs

Smoking cessation programs are also being delivered in the community, away from health centres, in order to provide a holistic, health-oriented, rather than a disease-oriented, focus (Ivers, 2001). There are a growing number of such initiatives, with most of the projects in this literature review occurring in the local community, with the associated benefits ensuing.

A good example is the 'Tiwi for Life Project', which employs community health workers to educate community members about the effects of tobacco (Ivers, 2001). Though this program, like other such programs, has not been formally evaluated for its effect on tobacco use, an achievement is the community development involved, including strengthening of the community, skill development, education and training.

Another such program is the Gapuwiyak Men's Health Project (Guyula, Bryce, Duggan, & Jackson, 1999). The Gapuwiyak Men's Clinic in Arnhem land ran men's health programs that included talking to men about smoking and showing them educational videos. These programs were coordinated around the local community football club activities.

The Strong Women, Strong Babies, Strong Culture Program was piloted in three remote Indigenous communities in the NT (Mackerras, 1998). The antenatal care program incorporated advice on smoking cessation, including the use of a flip chart. The prevalence of low birthweight declined from 20% before the program to 11% after the program. Unfortunately, documentation did not include the prevalence of smoking at the end of the study period (that is, after the baby was born), as the focus of this particular intervention was antenatal care.

The Maningrida 'Be Smoke Free' Project aimed to describe the current practices, knowledge and attitudes regarding tobacco use in school-aged children from remote Aboriginal communities in the Top End (Johnston, Beecham, Dalgleish, Malpraburr, & Gamarania, 1998). The project developed an educational intervention program about tobacco use for school children that would be adaptable to other remote Aboriginal communities.

In spite of, or perhaps because of, the high prevalence of smoking in Indigenous communities in the Top End, there was considerable interest, enthusiasm and potential for successful smoking prevention programs. All participating communities were keen to support new initiatives to address the problem, and educational intervention was extremely popular with children and adults in all three communities targeted.

An interesting example from central Australia is 'The Lung Story' project, which utilised a community development approach and incorporated traditional Indigenous artwork to create promotional and educational materials (Gill & Inkamala, 1998). Unfortunately, the project was not evaluated for changes in behaviours or attitudes to tobacco use.

State and Territory programs

The NT Tobacco Action Project (TAP), which is involved in a range of anti-tobacco activities, employs Indigenous health promotion officers to deliver programs for Indigenous people (Ivers, 2001). It also provides funds for the development of community-based programs by Indigenous communities.

The 1994 WA Quit Campaign was the first Australian media campaign to specifically target Indigenous people, with strategies including a newsletter, distribution of resources, radio advertisements and incentives for Aboriginal Health Workers to quit smoking (Health Department of Western Australia, 1997). Unfortunately, neither this or subsequent media campaigns have yet been evaluated.

The Jabby Don't Smoke project was developed by the Kimberley Public Health Unit (a Unit of the WA Department of Health) to provide appropriate resources for teaching smoking prevention to young Aboriginal people living in these remote communities in the Kimberley region of WA (Dale, 1999). The project includes mass media advertising and live performances by puppet characters in remote community schools. A formal evaluation has been conducted and documented. An important achievement of the project has been the increased communication and social trust between schools and the Public Health Unit, which has assisted in raising awareness of smoking as a significant health issue.

Projects such as this, which have been formally evaluated, demonstrate that the provision of appropriate resources may perhaps be the best option for health promotion when targeting people living in remote locations where staff turnover is high.

Fresh Start, the program designed by Quit Victoria for the general population, was adapted for Indigenous people (Briggs, 1996). The adaptation included a training course for health staff who wanted to conduct quit courses specifically for Indigenous people, and the production of a smoking cessation pamphlet, the Koorie Can Quit Book which was sent to Aboriginal health agencies in Victoria along with other relevant resources.

Summary

In response to the high prevalence of tobacco use among Indigenous people and the associated high levels of mortality and morbidity, there are increasing numbers of Indigenous-specific tobacco control programs/projects being implemented in Australia. This review has summarised a number of small programs, the most popular of which appear to be in the area of health promotion (with a particular emphasis upon the development of educational resources).

There is an abundance of literature on the effectiveness of a range of tobacco interventions in other populations, but, by October 2001, there were only three interventions that had been formally evaluated in Indigenous communities (Ivers, 2001). This general lack of evaluation of tobacco interventions in Indigenous contexts, and the fact that there appears to be little or no integrated coordination of these programs, makes it extremely difficult to form any conclusions regarding achievements in the area of tobacco use (Ivers, 2001).

The need for formal evaluation appears have been recognised, with increasing numbers of programs now undergoing a formal process (for example, the Queensland Health 'Indigenous Tobacco Control Project', The Tobacco Book, Territory Health Services Tobacco Action Project, 'Say No to Smokes' project). These results are not yet available, but it is possible to extrapolate from interventions that have been effective for other populations. However, more research or evaluation is required to ensure that such interventions are indeed effective for Indigenous people (Ivers, 2001).

Programs that have been successful with Indigenous people – across a range of health issues – are those that are compatible with Indigenous social and cultural values and aspirations. Successful programs reinforce and support traditions and priorities rather than imposing external solutions. Successful programs were also regarded as those run in areas where the community was ready to take the issue on and that were well financed. One could extrapolate from this 'theme' that interventions targeting tobacco use would be expected to follow suit. The limited evidence uncovered in this literature review indicates that this is indeed the case.

Despite the lack of formal documentation, the ever-increasing number and quality of projects being implemented across Australia and the support and interest of the Indigenous people involved should be seen as achievements.

As Ivers concludes: 'Because of the high rates of tobacco use in Indigenous communities, the relative lack of exposure to Quit messages, and the potential to develop momentum through community projects, it is possible that community-based tobacco interventions in Indigenous contexts may be more likely to succeed than those elsewhere' (Ivers, 2001, p.68).

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Illicit drug use[26]

Background

Illicit drug use was first noted by the 1989 National Aboriginal Health Strategy Working Party as an emerging problem for some Indigenous people (National Aboriginal Health Strategy Working Party, 1989), but its full impact was first documented as a supplement to the 1993 National Drug Strategy Household Survey. A special supplementary survey found that 51% of around 3,000 Indigenous people living in urban areas had ever tried an illicit drug, compared with 37% of the general population surveyed (1.6% of whom were Indigenous people) (Commonwealth Department of Human Services and Health, 1996).[27] Current use was reported by 24% of the Indigenous sample, and by 15% of the general population.

Marijuana was the most commonly reported illicit drug used by Indigenous people – 48% had tried it, and 22% were current users (Commonwealth Department of Human Services and Health, 1996). None of the other illicit drugs had been tried by more than 7% of the Indigenous sample, nor was used at that time by more than 2%.

Injected illegal drugs had been tried by 3% of Indigenous people, and were used at that time by 2%. These levels are slightly higher than those for the general population – 2% had ever tried and 0.5% were using at the time of the survey. Other evidence of possibly higher injecting drug use among Indigenous than non-Indigenous people comes indirectly from the notification rates for hepatitis C, the main mode of transmission being associated with use of contaminated injecting equipment. As noted in the section on hepatitis C, the crude

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[26] Illicit drugs include amphetamines (speed: for non-medical uses), cocaine, sleeping pills/tranquillisers (for non-medical uses), marijuana, analgesics (for non-medical uses), heroin, petrol and other inhalants, hallucinogens, and designer drugs (National Aboriginal Health Strategy Working Party, 1989).

[27] It is important to note that this survey related to the capital cities and other urban areas. It is likely that the use of illicit drugs, particularly injected drugs, is lower in rural and remote areas of Australia.

notification rate of 19.2 per 100,000 for Indigenous people living in WA, SA and the NT in 1998-2000 was more than 3 times the rate of 5.9 per 100,000 for non-Indigenous people.

Achievements

As with many other areas of Indigenous health, this review could not locate any evidence of achievements in terms of reduced use of illicit drugs or of reduction of harm from their use.

On the other hand, the increasing awareness of the prevalence and impact of illicit drug use among some Indigenous populations has resulted in a number of important responses. While none of the major initiatives under the National Illicit Drug Strategy are aimed exclusively at Indigenous people (Commonwealth Department of Health and Aged Care, 2001), individual treatment, education and research projects for illicit drug use by Indigenous people are incorporated. Examples include:

- funding under the non-government Treatments Grant Program has been allocated for 18 projects targeting Indigenous people (including treatment for heroin and petrol sniffing projects);
- funding under the Community Partnership Initiative Program for 13 projects targeting young Indigenous people;
- a study to assess the attractiveness of new pharmacotherapies to Indigenous illicit drug users;
- the implementation of diversion programs nationally for education, early intervention and treatment of illicit drug offenders; and
- the development of training packages to increase the awareness, skills and knowledge of Indigenous health workers working with illicit drug users and those affected by their use.

As well as national initiatives like these, a number of studies and projects have started to explore local aspects of illicit drug and possible responses (Edwards, Frances, & Lehman, 1999; Larson, 1996; Larson & Currie, 1995; Larson & Eldridge, 1999; Shoobridge, Vincent, Allsop, & Biven, 1998). A recent report canvassed a range of harm reduction options for Indigenous people who inject drugs in WA (Gray et al., 2001).

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Petrol inhalation

Background

Petrol inhalation ('sniffing') – a 'risk behaviour' and a form of volatile substance use (VSU) – is practiced by a significant minority of young Indigenous people across Australia and in other countries.[28]

Petrol sniffing in Aboriginal communities: a review of interventions describes the context of petrol sniffing for Indigenous people (d'Abbs & Maclean, 2000). The majority of Indigenous petrol sniffers are males and most are aged between 8 and 30 years. Sniffing is most prevalent among people in their late teens with sniffers of an older age more likely to be chronic sniffers. Petrol sniffing can have short-term and long-term consequences (Brady & Torzillo, 1995; d'Abbs & Maclean, 2000). It can be the cause of mental and physical impairment, poor educational performance, and family and community problems (including vandalism, violence and reduced morale). Strategies that are successful in one community may not be successful in another, due to a variety of variables. There is evidence of reduction of the problem in some communities, particularly those with strong community support.

Recent developments and achievements

There have been a number of successful strategies, which involve the use of a range of interventions (d'Abbs & Maclean, 2000). These address the areas of:

- drug (pharmacological-toxicological properties);
- set (personality and physical health); and
- setting (social and physical environment) (Zinberg cited in d'Abbs & Maclean, 2000).

Most successful interventions are initiated by the community, enjoy widespread community support, and involve strong participation of community members (d'Abbs & Maclean, 2000). Recreational and employment programs for young people have often been effective primary prevention programs.

The substitution of petrol with Avgas/Comgas (aviation gas or Comgas, as it is called to distinguish its use by communities for non-aviation purposes) as a supply control strategy has, in some communities, been the most successful means of limiting young people's access to petrol (d'Abbs & Maclean, 2000). This has not been successful, however, in all communities. Sniffing Avgas causes severe head and stomach aches. Using unleaded petrol is a controversial strategy, because, although it is thought there is less chance of neurological damage, the risks are unclear.

Some interventions – such as locking up petrol supplies or adding deterrents to petrol – have not been as successful, for a variety of reasons (d'Abbs & Maclean, 2000). Secondary interventions (warden schemes, night patrols and using police aides to identify sniffers and return them to their families) can be successful as temporary measures. Using Indigenous culture and symbolism to increase knowledge about petrol sniffing are interesting and innovative ways of addressing the problem and have achieved the participation of community members, but have not been evaluated.

Counselling and community development, including the use of the HALT (Healthy Aboriginal Life Team) model (Franks, 1989), have had mixed results (d'Abbs & Maclean, 2000). Community-based sanctions (physical punishment, shaming and banishment) and jail sentences seem to have mainly short-term effects. Tertiary preventive strategies, including

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[28] The inhalation of other volatile substances - such as glues and solvents - is not uncommon among Indigenous children, but there is very little literature on the subject.

sobering up centres, respite services and hospitalisation, have had only limited success in treatment and rehabilitation, highlighting the need for more effective primary intervention.

Each community dealing with petrol sniffing is unique, and there are complex issues impacting on rates of success (Roper & Shaw, 1996). Accumulating knowledge of these issues assists in creating understanding (Dear, 1997). The perspective of non-Indigenous people working in this area should also be taken into account.

An evaluation of strategies carried out in the Maningrida community in the NT found that replacing petrol with Avgas in the fuel supply was a key element in eliminating petrol sniffing (Burns, Currie, Clough, & Wuridjal, 1995). Four months after the introduction of Avgas, petrol sniffing had ceased and the incidence of related crime had fallen. Its apparent lack of success as a single intervention elsewhere, however, indicates the importance of widespread community resolve against petrol sniffing and the development of coordinated employment and skills training strategies.

The aim of the Petrol Link-Up Project was to find out issues related to petrol sniffing through: collating and disseminating information; developing a regional history of petrol sniffing and interventions; identifying strategies to access resources; developing a resource package for communities about petrol sniffing; establishing networks and planning and organising two workshops (National Drug Strategy, 1994). The project was evaluated according to performance indicators. All the aims and objectives were met and some were developed more than anticipated.

Probably the most exciting development over the past decade has been the leadership of Indigenous communities in designing and implementing programs addressing petrol inhalation. In many ways, the challenge is to combine the old with the new, mixing strategies and practices from Indigenous culture that are seen to help sniffers together with whatever can be found to be useful from western systems (d'Abbs & Maclean, 2000).

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6.2 General health aspects

Maternal and child health

Background

There have been some improvements in Indigenous maternal and child health in recent years, but the health of young Indigenous mothers and their children is still at an unsatisfactory level compared with their non-Indigenous counterparts. This overview highlights some of the successful elements which have been achieved in the area of maternal and child health encompassing breastfeeding, foetal growth, all stages of pregnancy, and infant and child growth.

Adequate nutrition is important at all stages of development, including intra-uterine life. Malnutrition of a mother and risk factors (such as smoking, consumption of alcohol and other substances) during her pregnancy can cause intra-uterine growth restrictions and may contribute to health consequences for the child later in life (National Health and Medical Research Council, 2000). The low birthweight of many babies, resulting from intra-uterine growth restriction or a short gestation period (or both), may lead to an infant's death or ill-health throughout infancy and childhood.

Adequate nutrition during infancy and childhood is essential for normal growth – it is well established that infant and child malnutrition impact heavily on growth retardation and immune deficiency, which in turn predisposes such children to a wide range of infectious diseases. Malnutrition is also suggested as being associated with a higher risk of diseases later in life (for example, diabetes mellitus, hypertension, heart disease and kidney disease) (Taylor, 1999). Breastfeeding is encouraged as it has been associated with a reduction in infant and child mortality. Child growth is also affected by several other factors including environmental and genetic influences. Persistent negative environmental influences may lead to 'failure-to-thrive' or malnutrition, together with specific nutrient deficiencies and anaemia (National Health and Medical Research Council, 2000). Infants born prematurely or who are growth restricted at birth have a much higher requirement for iron (given that their iron stores are lower and subsequent growth may be more rapid (Edmond, White, & Paterson, 2001).

Many factors influence the level of malnutrition experienced in remote Aboriginal communities, including 'food availability, lack of appropriate knowledge, poverty, inability to plan expenditure over a fortnight, gambling, and lack of health hardware, cooking and storage facilities' (Warchivker, 2000). Given the number of factors contributing to child malnutrition, it has been stated that to deal with just one component may be of limited value and that a solution to nutrition problems cannot be found in the medical paradigm alone (Warchivker, 2000).

Achievements of general programs

Several projects and interventions have resulted from communities' concerns about the health and wellbeing of young children and their mothers, particularly the younger mothers in the community. When experience and advice detailed in consultations with community members have been taken into account, projects have achieved positive outcomes. Such projects appear to have been keenly accepted by the community, particularly where local women have been involved in the project and have acted as role models. Working with communities and acting on their recommendations has acted to build a sense of ownership by the local communities.

This was seen in the Koori community with the commencement of a program to reduce the level of recurrent infections in young children (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). After extensive consultation with the community, this program resulted in the production and dissemination – by local women – of various resources such as a video, poster and booklet. This strategy provided the community women with role models, that they felt comfortable with, to approach for advice and support.

The value of traditional cultural practices and the knowledge and experiences of older Aboriginal women have been recognised and acknowledged. Combining traditional Aboriginal practices with western knowledge and services has resulted in positive outcomes through some programs (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). This approach was the basis on which the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council (NT) developed its nutrition awareness project for young mothers and children. The project, initiated by the senior women in the community, aimed to reduce the incidence of 'failure to thrive' in remote communities in the NPY lands of central Australia. Through their experience, the senior women felt they were in a position to help younger mothers gain a better understanding of the needs of their children. The project consisted of several components including the promotion of bush tucker as a basis of the children's diets. Workshops with young mothers helped them become more comfortable with visiting clinics for general advice and the weighing of their babies.

Partnerships have been formed through various projects that have used a multi-disciplinary, multi-agency approach to achieve positive results. A nutrition intervention in a central Australian community used such an approach to target children under the age of five years, and specifically those at risk of malnutrition (Warchivker, 2000). During the first year of the program, a 70% decline in hospital admissions due to gastrointestinal and nutritional problems was reported, and these results were sustained during the second year.

In many cases, projects have provided the opportunity for local Indigenous health workers to be trained in specific maternal and child health issues which has provided community members with access to a local person for advice and support. Workforce development has also been undertaken in these areas for Indigenous health workers with courses being offered by institutions such as the Marr Mooditj Foundation Inc. in Perth, WA (Turnbull & Select Committee on Intervention in Childbirth, 1995). Students are trained in areas of antenatal, birth and postnatal care and attend a workshop at King Edward Memorial Hospital for Women. An optional maternal health unit, offered as part of a diploma course, includes two weeks of practical training in a hospital. The course has been also adapted to two-week study blocks for students travelling to Perth from country areas.

An exceptional example of a program which exhibits several elements of success is the 'Strong Women, Strong Babies, Strong Culture' program (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). Through this program, the proportion of pre-term birth has been reduced and birth weights increased (an increase in the mean birthweight of 141grams and a decrease in the proportion of low birthweight from 30% to 11.5%). This program has seen women participate in antenatal care at an earlier stage of gestation.

The 'Strong Women' Strong Babies, Strong Culture' program, which was developed through consultation with health workers and Aboriginal women, has seen the training of women in the community who act as 'Strong women workers' (SWW) (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). These workers provide expectant mothers with support and encouragement to visit the clinic – in some cases driving them there – and attending the consultation, if requested. The SWWs also advise and encourage pregnant women to adhere to prescribed medications and to eat nutritiously by incorporating bush foods into her diet, even organising trips to collect these foods (Mackerras, 1998). The role of the SWW is seen as a bridge between the clinic and the community. It has been reported that one of the main strengths of the program has been selecting the right people to fulfil this role. The program has worked also to contribute to self-esteem within the community, and pride in the fact that they are doing things for themselves.

Dedicated services for Indigenous mothers have been received positively, and have worked to provide greater access to services – in some cases at earlier stages of pregnancy. The launch of services such as the 'Early Parenting and Birthing Services Directory' by Macquarie Area Health Services in NSW has worked to ensure that pregnant Aboriginal women in the area have access to a range of services that are appropriate to their needs (Campbell, 1998). The directory provides clients with the names and contacts of Aboriginal health services, antenatal services, prenatal services, postnatal services and early childhood services. These services are delivered in a culturally appropriate manner and the directory ensures that clients are aware of all the services that are available to them and their families. Such a service has been able to guide new mothers into seeking the most appropriate services for their individual needs, therefore assisting in the prevention of possible problems for mothers and their baby.

The 'Aboriginal Birthing on Homelands' project commenced in 1991 and was initiated to address the issue of birthing services in Aboriginal communities (King et al., 1998). It involved five communities and consultation with the women of these communities. Reports evolving from the consultations provided the background for a clinical needs assessment, which was undertaken in 1997, to determine the level of existing maternal health services within each of the communities and to further progress the project. Based on the findings of the needs assessments and to facilitate the development of quality services, specifications of the 'Delineation of maternal health services in Aboriginal communities' and 'Standards for maternal health services in Aboriginal communities' were developed (King et al., 1998).

Programs aimed at breastfeeding

Overall, the prevalence of breastfeeding among the Indigenous population is significantly lower than that of the non-Indigenous population (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). The exception to this is in communities where a 'traditional' lifestyle has been maintained. Indigenous mothers traditionally breastfed their babies exclusively for at least six months, with some feeding through to the age of four years. Since colonisation, this practice has changed dramatically (Holmes, Phillips, & Thorpe, 1997a).

The benefits of breastfeeding have been clearly established. These include assisting in the prevention of gastrointestinal, chest, ear and urinary tract infections in infants (Holmes et al., 1997a). Breastfeeding is recommended particularly for babies with a low birthweight or whose mother has diabetes (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). Given the potential benefits, several programs have been implemented to promote breast-feeding among the Indigenous population. It is evident from the literature that many of these programs have achieved favourable outcomes.

An important collaborative study was undertaken by the Indigenous Health Program, Inala (southern Brisbane) to investigate Indigenous breast-feeding and weaning practices in an urban setting (Hayman, Kanhutu, & Bond, 1998a). This study was able to examine various factors relevant to breast-feeding and weaning, and to assess the proportion of low birthweight babies, smoking and alcohol consumption among Indigenous mothers, their access to health information, and their use of medical services. The study, which was culturally appropriate and strengthened by community support, had a response rate of 90%. The findings of the study were the basis for the development of the 'Eating well for you and baby' booklet, and may act as the foundation of future educational initiatives (Hayman, Kanhutu, & Bond, 1998b).

Programs that have aimed to encourage initiation and duration of breastfeeding have shown some positive results. Data collected over a three-year period through the DjuliGalban program in the north coast of New South Wales indicated that breastfeeding rates at discharge and at six weeks increased from 30% in 1993-94 to 44% in 1995-96 (these rates include those who were both breast- and formula-feeding) (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1998). Immunisation rates also increased, as had the number of clients using the early childhood and immunisation services.

The literature suggests that programs relating to maternal and child health have a far greater impact when there is an understanding of the wider social and cultural issues. For example studies into breastfeeding suggest that interventions should be aimed not at trying to persuade Indigenous mothers to breastfeed, but at addressing barriers to breastfeeding (Holmes, Thorpe, & Phillips, 1997b).

It has been recognised also that programs that have been successful in the general population may not have achieved any similar results within the Indigenous population, reinforcing the need for culturally-specific interventions. This aspect was addressed in the Bibbulung Gnarneep research project in Perth, WA (Bibbulung Gnarneep Team, 1997). Results from the sudden infant death syndrome (SIDS) 'Reducing the risks' intervention campaign, which was aimed at the total population, showed a marked decrease in the rate of SIDS within the non-Indigenous population but not within the Indigenous population. This prompted the Bibbulung Gnarneep project, involving collaboration between the Aboriginal community (represented by the Perth Aboriginal Medical Service (now Derbarl Yerrigan) and the Marr Mooditj Aboriginal Health Worker College) and the TVW Telethon Institute for Child Health Research. By collecting information on infant and child care practices through interviews with mothers from when their babies were six weeks old through to approximately two years of age, the project aims to obtain a better understanding of infant care practices and to assist in the development of culturally appropriate interventions.

Lessons have been learned also through the evaluation of projects which not been entirely successful. The evaluation of a health and nutrition education program for Aboriginal mothers in remote north-west Australia found that there had been little improvement in the knowledge of the participants after the program, and that there was no evidence that the program had altered maternal attitudes or behaviour towards health (Gracey & Sullivan, nd). The evaluation found that communication difficulties had been experienced between the non-Indigenous health professionals and the participating Aboriginal women, with the health professionals using words which were poorly understood by the women. The evaluation highlights the need for culturally appropriate interventions, including the recognition that participants may have had limited formal education and that English may be their second or third language.

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Mental health, including social and emotional wellbeing

Background

The Indigenous view of mental health is a holistic one, as embodied in the general definition of health as:

> …health is not just the physical wellbeing of an individual, but 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.

Mental health programs, policies and initiatives that have recognised and encompassed the importance and implications of this culturally significant difference in the concept of mental health have a much better chance of achieving their goals than those that try to enforce a western model of mental health. The recent use of the term 'emotional and social wellbeing' reflects an increasing understanding of the need for mainstream services and policy makers to recognise the Indigenous holistic concept of mental health. The term 'emotional and social wellbeing' will be used in this review interchangeably with 'mental health', depending upon the term of reference chosen by the particular program, policy or report being discussed.

'The impact of colonisation inflicted on Aboriginal and other oppressed Indigenous people, such as the American Indians and New Zealand Maoris, includes a wide range of emotional, social and behavioural outcomes. These include; high suicide rates, mental health problems, alcohol misuse, child neglect and violence with families and communities' (Franks, 2001).

Awareness of the cultural diversity that exists *within* the Indigenous population as a whole, and specifically between individual communities throughout Australia, is required when addressing the complex area of mental health. This cultural diversity is particularly significant to the issue of 'standard applicability' of any mental health tools/instruments/methods that may be developed.

The literature identifies two separate but interlinked areas of need in mental health care for Indigenous Australians. One area is broad and all-encompassing, including social and emotional problems such as anxiety, mild depression, and substance abuse, and the other area includes serious mental illnesses (such as schizophrenia and severe depression).

General goals

Enhanced understanding, profile and 'literacy' of social and emotional wellbeing among Indigenous people, policy makers and health care professionals are just some of the goals common among Indigenous 'mental health' interventions. The following list, in which there is overlap and which is by no means exhaustive, includes other common goals of mental health interventions:

- Reduction in the rates of suicides, suicidal thinking, suicidal behaviour, injury and self-harm (generic goal – not specific to one program in particular)
- Enhanced resilience in individuals, families and communities (generic goal – not specific to one program in particular)
- Increased support to those affected (generic goal – not specific to one program in particular)
- Extended and enhanced community and scientific understanding of suicide and its prevention (generic goal – not specific to one program in particular)
- Improved education and subsequent knowledge of trauma, loss and grief and how they effect Indigenous people (New South Wales Department of Health, 1997)
- Increased number of Indigenous people utilising mental health services (New South Wales Department of Health, 1997)
- Increased resources for suicide prevention programs in Indigenous communities and feedback and evaluation of services developed by people involved in the program (Commonwealth Department of Health and Aged Care, 2000a)
- Accumulation of feedback by participants on the cultural appropriateness of training and services (Commonwealth Department of Health and Aged Care, 2000)
- Increased numbers of people in Indigenous services and communities, and mainstream services, who have received training in prevention of suicide and self harm (New South Wales Department of Health, 1997)
- Improved access to mental health services (New South Wales Department of Health, 1997)
- Indigenous people involved in the care of Indigenous clients (New South Wales Department of Health, 1997)
- Indigenous service users to receive appropriate referrals (New South Wales Department of Health, 1997)
- Improved accuracy of data collection for identification of Indigenous status (New South Wales Department of Health, 1997)
- Involvement of Indigenous people in the planning of mental health services for Indigenous people and recruitment of Indigenous mental health workers (New South Wales Department of Health, 1997)
- Improved knowledge of mental health services by Indigenous people (New South Wales Department of Health, 1997)

National context

There have been several major reports over the past decade or so addressing the issue of Indigenous mental health. All reports identify the need for increased and improved services for Indigenous people. These reports have been listed below in chronological order.

National Aboriginal Health Strategy (1989)

The National Aboriginal Health Strategy (NAHS), prepared by the National Aboriginal Health Strategy Working Party, sets out specific guidelines and recommendations for the provision of mental health services to Indigenous peoples.

An evaluation of the NAHS, completed in December 1994, found that the Strategy had been inadequately implemented and had a limited focus, as a result, many inequities and needs in Indigenous health remained (O'Neil, 1996).

Report on the Royal Commission into Aboriginal Deaths in Custody (1991)

The Commission investigated the deaths of 99 Indigenous people in the custody of police, prison or juvenile detention institutions between 1980 and 1989. It looked into the circumstances of the deaths, action taken by authorities following the deaths and underlying causes, including social, cultural and legal factors. The Commission's report made a number of recommendations related specifically to Indigenous mental health (O'Neil, 1996).

This report has had an impact on many subsequent government and private mental health initiatives and policies, and has resulted in numerous follow-up/implementation reports, including two by the Human Rights and Equal Opportunity Commission (*Indigenous Deaths in Custody, 1996* and *Bringing Them Home, 1998).*

National Mental Health Plan (1992)

The National Mental Health Plan addresses a range of issues fundamental to the planning and delivery of mental health services in Australia. It identifies critical steps for the reform of services, with one of the key priorities to target the needs of Indigenous people (O'Neil, 1996).

Report of the National Inquiry into the Human Rights of People with Mental Illness (Burdekin Report, 1993)

This report, completed by the Human Rights and Equal Opportunity Commission in 1993, found that in many areas the human rights of individuals affected by mental illness were being ignored, eroded or seriously violated.

Chapter 23 of the report looks specifically at issues affecting Indigenous people, including their historical experience and the consequences of colonisation, the ethnocentricity of existing approaches to diagnosis and treatment of mental illness, and the social context of Indigenous mental health problems. Based upon these findings and the recognition of the particular mental health needs of Indigenous people, the report makes numerous recommendations (O'Neil, 1996).

National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health (Ways Forward, 1995)

This report followed the National Aboriginal Mental Health Conference (1993), and incorporated many of the insights and recommendations supported by Indigenous people present at the conference. The report outlined a range of policy proposals for Indigenous mental health, which rest on numerous guiding principles including: the concept of health and mental health as holistic; the central importance of self-determination; and the provision of services based upon culturally valid understandings. Many of the proposals build on findings and recommendations from earlier reports. The *Ways Forward* report provides a contextual understanding to the special mental health needs of Indigenous people (O'Neil, 1996).

National Youth Suicide Prevention Strategy (1995)

The Commonwealth Government's National Youth Suicide Prevention Strategy (NYSPS) aimed to reduce rates of youth suicide and self-harming behaviours in Australian youth, and influence the way other programs, agencies, and individuals deliver prevention programs to young people at risk.

Of seventy projects funded under the NYSPS, the title or auspicing organisation of four indicates a focus on young Indigenous people, and several others were located in or near substantial Indigenous communities. Young Indigenous people were declared the target group for the 'Here for Life' program, the first national program in response to youth suicide, which began in 1995.

Aboriginal and Torres Strait Islander Emotional and Social Wellbeing (Mental Health) Action Plan (1996)

Launched by the Commonwealth Government in 1996, approximately $20.5 million was provided over 4 years to implement the Aboriginal and Torres Strait Islander Emotional and Social Wellbeing (Mental Health) Action Plan, with implementation and oversight undertaken by OATSIH. The main thrust of the plan was the development of infrastructure that would enable the growth of culturally appropriate high quality emotional and social wellbeing services for Indigenous people.

Expected outcomes included establishment of a national network of Regional Training Centres for Indigenous emotional and social wellbeing and the development of Indigenous mental health data and information systems.

There has been a great deal of activity since the launch of the plan, even more significant given the low base from which the field started – emotional and social wellbeing generally not being distinguished from mental health in 1995.

Under the plan, a range of initiatives has been supported including responses to the recommendations of some earlier reports. Programs have included support for the *Deadly Sounds* radio program, trauma and grief counselling services, specialised regional mental health training centres, development of culturally sensitive counselling models, and parenting programs.

Due to the 'infancy' of the social and emotional wellbeing field, it is too early to assess whether the emotional and social wellbeing of Indigenous individuals and communities have improved.

However, the core direction of the Action Plan has demonstrated effectiveness and offers the promise, in the long run, of improving the wellbeing of Indigenous people.

Bringing Them Home (1998)

The Bringing Them Home report, by the Human Rights and Equal Opportunity Commission, followed on from the recommendations of the Report on the Royal Commission into Aboriginal Deaths in Custody (1991). The *Bringing Them Home* report called for culturally appropriate community-based and mainstream mental health services, the development of parenting programs, safeguards against the removal of children, diversion from custody programs and support for Indigenous prisoners.

Second National Mental Health Plan (1998)

The Second National Mental Health Plan was developed to provide a national framework for future activity in mental health service reform and is a five-year (1998-2003) extension of the National Mental Health Plan (1992). It is envisaged that implementation of the second plan will contribute significantly to improved treatment, care and quality of life for Australians with mental illness, their families and the general community. Though not specifically Indigenous-focused, the plan does contain consultative mechanisms and links in the areas of Indigenous mental health and suicide prevention.

The Plan provides a national framework for future activity in mental health service reform, mental health promotion, prevention and early intervention. It ensures better partnerships within mental health services, and between mental health services and other health services, consumers, families and other sectors. The Plan intends to respond better to the mental health needs of specific populations, including Indigenous people.

Mental Health Promotion and Prevention National Action Plan (1999)

This Commonwealth Government project provides a policy framework for mental health promotion and prevention under the Second National Mental Health Plan. The Plan addresses initiatives across population groups, including Indigenous communities. The Promotion and Prevention Working Party includes a NACCHO representative.

Living Is For Everyone (LIFE) (2001)

Living is for Everyone (LIFE) is a framework for prevention of suicide and self-harm in Australia over the period 2001-2005 (Commonwealth Department of Health and Aged Care, 2000a). LIFE builds on the work of the National Youth Suicide Prevention Strategy and includes three companion documents: Areas for Action; Learnings about Suicide; and Building Partnerships.

The LIFE Program aims to reduce suicides, suicidal thinking, suicidal behaviour, injury and self-harm, enhance resilience in individuals, families and communities, and increase support to those affected. In addition, the program hopes to extend and enhance community and scientific understanding of suicide and its prevention.

LIFE has declared partnerships with Indigenous peoples to be one of its six 'Action Areas'. While maintaining a focus on youth suicide, LIFE broadens the scope of activity to include prevention and intervention across the lifespan for Indigenous and non-Indigenous people.

Initiatives in the Indigenous focused 'Action Area' are intended 'to provide culturally appropriate programs (universal, selective and indicated) which support community responses to high rates of suicide in Aboriginal and Torres Strait Islander communities' (Commonwealth Department of Health and Aged Care, 2000b, p.58).

Achievements

The following programs have been reported to have made a difference in the lives of those targeted – that is an achievement has been made in the field of mental health through their initiatives/interventions.

Family Life Promotion Officer Program (Harrison, Miller, Weeramanthri, Wakerman, & Barnes, 2001)

Clusters of suicide in the Yarrabah (North Queensland) community during the early 1990s engendered a sense of crisis, which persisted for several years. A critical stage in reaction came with the community-based response of the Family Life Promotion Officer Program. This program achieved a shift from 'simply attempting to identify individuals at risk and dealing with crises as they developed to focusing on a condition of risk impacting the community as a whole' (Harrison et al., 2001, p.61).

Though a formal documented evaluation has not been found in the literature, the program has achieved positive results including the following:
- community acceptance of suicide as an issue demanding attention;
- introduction and development of Life Promotion Officers;
- closure of the community canteen (the alcohol outlet);
- suicide case numbers decreased; and
- steep decline in the numbers of presentations of threatened or actual self-harm to the Life Promotion Officer at Yarrabah.

Family Wellbeing (Harrison et al., 2001)

Family Wellbeing is a course designed by and for Indigenous Australians to promote personal empowerment. It was implemented in Alice Springs in 1998 as part of a response to the increased number of suicides and attempted suicides in Indigenous communities.

An evaluation of the program has been published (Tsey & Every, 2000). The evaluation focused on qualitative assessments of skills, satisfaction and attitudes of course participants. The evaluation also documented the development and implementation of the program. The evaluators concluded that the following had been achieved:
- improvement of participants' capacity in life skills and problem solving; and
- completion rates of the four stages of the wellbeing course gave a positive quantitative measurement of achievement.

Community Gatekeeper Training (Capp, Deane, & Lambert, 2001)

Concern over the high rate of suicide among Indigenous people on the south coast of NSW led to the development of a project aimed at preventing youth suicide in the Indigenous communities of the Shoalhaven. Following extensive consultation with the Indigenous community, a range of culturally appropriate interventions were developed. The main focus was a series of community gatekeeper training workshops, which aimed to increase the potential of members of the community to identify and support people at risk of suicide and to facilitate their access to services.

Evaluation of the workshops demonstrated the following achievements:
- an increase in participants' knowledge about suicide;
- greater confidence in identification of people who are suicidal; and
- high levels of intentions to provide help.

Victorian Aboriginal Mental Health Network (VAMHN) (McKendrick & Thorpe, 1994; McKendrick et al., 1990)

The Victorian Aboriginal Mental Health Network (VAMHN) was a unique mental health program for Aboriginal people in Australia, as it was based within the Aboriginal community it served, while utilising resources from mainstream services.[29]

In the years following its establishment in 1987, the VAMHN developed a wide range of services and programs, which were highly successful. Achievements included the following:
- overwhelming support from Aboriginal people, both locally and across Australia;
- development of a wide range of services and programs including a community consultation unit and an inpatient unit – utilisation of inpatient and outpatient services increased each year;
- educational seminars in Aboriginal culture and health, and general mental health issues, catering for a wide range of audiences; and
- an on-going community evaluation and research program.

Conclusions

Important achievements have been made in Indigenous mental health, as shown in this review, and a number of promising initiatives are underway. There is still a long way to go, however, before

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[29] The Resource Unit for Indigenous Mental Health, Education and Research (RUIMHER) developed as a result of the VAMHN, but the network itself does not appear to exist now.

substantial improvements will be seen Australia-wide. Funding is an obvious necessity, yet it appears that this is still a major barrier for strategies addressing mental health and social and emotional wellbeing.

In order to further improve the mental health status of Indigenous people, there is a need to recognise and support the goals and aspirations of Indigenous people towards self-determination and self-management (Franks, 2001). The prerequisite for trust (attained usually by the involvement of Indigenous people/communities) has been demonstrated in achievements made so far. In order for a program to be successful, trust is a basic ingredient, especially when dealing with the sensitive and complex area of mental health. The current challenge is to recognise these interventions as achievements, to build upon them, to strengthen and support them, and expand their targets. The successful programs should be seen as models, which, if utilised to their full potential, can contribute more widely to improving Indigenous mental health.

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6.3 Chronic conditions

Cardiovascular disease

Background

Cardiovascular disease (CVD) refers to heart, stroke and vascular diseases, comprising 'all diseases of the heart and blood vessels including coronary heart disease, stroke, heart failure and peripheral vascular disease, that are caused by a damaged blood supply to the heart, brain and legs' (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999, p.ix). Of these degenerative forms of CVD, severe coronary heart disease (also known as ischaemic heart disease) can result in myocardial infarction (heart attacks). In contrast to the common forms of CVD, rheumatic heart disease results from damage to the heart valves secondary to episodes of acute rheumatic fever, itself an abnormal immune response to infection with group A streptococcus (Stollerman, 1997).

Most degenerative CVD is preventable, resulting from cigarette smoking, being physically inactive, eating a diet high in saturated fats, and/or being overweight (Australian Institute of Health and Welfare, 2000). Acute rheumatic fever is also preventable, and the disease (and resultant rheumatic heart disease) is now very rare in developed countries, except among 'deprived communities' (Stollerman, 1997).

Of the major risk factors for degenerative CVD, smoking is more than twice as common among Indigenous people than among non-Indigenous people. Poor nutrition is a factor also for Indigenous people, at least partly because of the limited availability and expense of nutritious foods in rural and remote areas where many Indigenous people live. It is not surprising, therefore, that CVD is the leading cause of death among Indigenous people (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

Rheumatic heart disease is an important and entirely preventable cause of morbidity and mortality among Indigenous people in Australia. The prevention of rheumatic heart disease requires concerted, ongoing intersectoral efforts by all levels of government and researchers (Ring & Firman, 1998).

To this end, the World Health Organization recommends best practice that involves implementation of a coordinated, register-based control program. This would involve '…establishment of primary health care service-oriented programs that include: a centralised register of all patients; case finding of those with acute rheumatic fever and rheumatic heart disease and coordination of secondary prophylaxis and clinical follow-up (including surgery); surveillance for new cases of acute rheumatic fever, rheumatic heart disease and group A streptococcal epidemiology; integration of these services into the existing primary care network; and adequate laboratory support' (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999, p.121).

Excluding those living in remote areas, Indigenous people are more likely to have degenerative CVD than other Australians across all age groups (National Centre for Monitoring Cardiovascular Disease, 1999; Thomson, 2002). Rheumatic fever and rheumatic heart disease are rare among the Australian population overall, but the incidence and prevalence among Indigenous people living in the Top End of the NT, in the Kimberley region of WA and possibly parts of north Queensland are very high, even by world standards.

Mortality from cardiovascular disease was around 2.7 times higher for Indigenous than non-Indigenous people across Australia 2000, but, as noted above, the incomplete identification of Indigenous people in death registrations in some jurisdictions means that this is an under-estimate of the true difference. From the more detailed data available for deaths from cardiovascular disease for people living in WA, SA and the NT in 1996-1998, it is likely that rates were 3.3 times higher for Indigenous males and 2.8 times higher for Indigenous females than for their non-Indigenous counterparts (Thomson, 2002).

In terms of specific categories of cardiovascular disease, the differences in rates between Indigenous and non-Indigenous people were:

- coronary heart disease – 3.0 times higher for males and 2.8 times higher for females;
- stroke – 3.3 times higher for males and 2.3 times higher for females;
- rheumatic heart disease – 30 times higher for males and 22 times higher for females; and
- other cardiovascular disease – 3.5 times higher for males and 3.3 times higher for females.

Relatively few deaths among Indigenous people in 1996-1998 were attributed to heart failure and peripheral vascular disease.

Achievements

In terms of the degenerative forms of CVD, strategies focusing upon modifiable lifestyle choices are the most common reported in the literature and have the potential to significantly reduce the severity and incidence of the various conditions (Watson, Ejueyitsi, & Codde, 2001). Subsequently, screening programs are popular and appear to be achieving their goals, not only of identifying those at risk, but also raising awareness of CVD and educating the community about how to reduce the risk factors.

The Community Development Health Project is one such project that raised awareness in the community and also provided valuable data for comparison and future planning of interventions (Stephenson & Lenz, 1991). Another example is the Koori Heart Health Screening Program, an annual screening, support and educational program, that has achieved positive outcomes for the community involved (National Health and Medical Research Council, 1997).

As the Indigenous population is young (with 40% aged under 15 years), there is a great opportunity to implement longer-term strategies for preventing cardiovascular disease, especially through reducing modifiable lifestyle risk factors. The Burnie Take Heart Project is one such intervention that has identified this opportunity and is promoting physical activity and healthy eating among upper primary school children (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999).

Primary and secondary level interventions are the focus of the majority of cardiovascular disease intervention projects, with the goals of increasing the awareness of CVD and its associated issues, particularly lifestyle-related risk factors. The main targets for this information are Indigenous health workers (for example, Chronic Disease Strategy (Field & Gregory, 2000); Commonwealth Rural Health Education, Support and Training program (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999)) and Indigenous communities (for example, Educational CVD (Ah Chee, Burns, Angeles, & Benger, 1999)).

In WA, the Health Department, Heart Foundation and Divisions of General Practice are collaborating to increase awareness of early warning signs and risk factors for CVD among men in that State (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999). Such interventions (that is, raising awareness) are increasingly common, and are apparently welcomed by Indigenous communities, when they have been included and/or consulted in the planning and implementation processes. For example, elements important in the success of the Koori Heart Health Screening Program were community consultation, culturally sensitive/appropriate venues and materials, and the rapport and trust built between the Indigenous health workers, community health workers and the community (National Health and Medical Research Council, 1997).

A substantial increase in understanding of issues related to access to services has been achieved by the Marka Waiendi Project in SA (Morgan & O'Connor, 1999). This project successfully achieved its six objectives, which included identifying gaps in services, developing a more efficient interaction between hospitals and outreach services, and developing a patient process map. This information was then provided to the relevant Flinders Medical Centre departments to assist in the planning of better services at the Centre. The importance of such cultural sensitivity and awareness in planning health service delivery to

Indigenous people has continually been shown through the literature to be a key ingredient in effectiveness of all health related intervention programs.

A program along the lines recommended by the WHO for the prevention and management of rheumatic heart disease has been developed by Territory Health Services, researchers and the National Heart Foundation, with financial support from the Commonwealth (Commonwealth Department of Health and Aged Care & Australian Institute of Health and Welfare, 1999). Using a database on people with rheumatic heart disease and acute rheumatic fever, the program focuses upon tertiary prevention, particularly compliance with long-term prophylactic medication, as well as access to the program.

Another achievement in the area of RHD is the successful Rheumatic Heart Disease Information Package (RHDIP), which was funded by the Rural Health Support, Education and Training Project (RHSET). The package was shown to be largely responsible for the expansion of awareness and understanding of rheumatic fever and RHD (Angeles, 2000).

Two tertiary prevention interventions reported in the literature (also the only to report morbidity/mortality data) are medical intervention programs. One program administered prophylactic antibiotics to prevent repeat episodes of rheumatic fever (Neilsen et al., 1993), the other gave Coversyl to Indigenous people with hypertension and selected diabetics, and to non-diabetic, non-hypertensive people with progressive overt albuminuria (Hoy, Baker, Kelly, & Jacups, 1999). Both programs had positive results and stated the need for dissemination and replication of the programs as they were so effective in the targeted populations. The rheumatic fever prophylaxis program achieved particularly impressive reductions in morbidity and mortality over a six-year period.

Summary

The potential for improvements in cardiovascular health for Aboriginal and Torres Strait Islander people is demonstrated by the significant declines in cardiovascular mortality achieved among Indigenous people in New Zealand and the United States since the 1970s. International demonstrations such as these should give impetus for increased and sustained efforts in Australia.

Intervention programs must address also the fundamental disadvantage and poverty, which underlie so much ill health in the Indigenous community. Programs must consider education, the environment and cultural factors, as well as traditional health paradigms, for improvements in Indigenous cardiovascular health to be maximised.

Dramatic reductions in CVD mortality and morbidity have not yet been achieved, but steps that are being taken towards this goal have been shown to be successful. Awareness of CVD, its risk factors and issues of care amongst Indigenous health care workers, policy makers and Indigenous communities is gradually increasing. It is ultimately through these efforts that significant declines in mortality and morbidity will be achieved. The process is unfortunately gradual and multi-faceted. The success internationally with Indigenous CVD and the decrease of CVD mortality and morbidity among non-Indigenous Australians suggests that similar results are achievable for Indigenous Australians.

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Respiratory disease

Background

Respiratory tract diseases are major causes of illness and death in the Indigenous population and contribute to high rates of hospitalisation and mortality observed in almost all age groups. The rate of hospitalisation for respiratory conditions is extraordinarily high for Indigenous people. In WA in 1988-1993, for example, hospitalisation rates were up to 16 times higher for Indigenous people than for non-Indigenous people (Williams, Gracey, & Smith, 1997). Respiratory conditions accounted for around 8% of deaths among Indigenous males and females living in Queensland, WA, SA and the NT in 1997-1999, at rates around four times higher than expected based on all-Australian rates (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

In terms of specific respiratory conditions, both infective conditions (acute respiratory infections and pneumonia) and chronic diseases (asthma and chronic obstructive airway disorders) are important causes of hospitalisation and mortality.

It is the impact of invasive pneumococcal disease (manifest mainly as pneumococcal pneumonia), however, that demonstrates the enormous health disadvantages experienced by many Indigenous people, particularly young children. In central Australia, for example, rates of invasive pneumococcal disease are among the highest documented anywhere in the world (Torzillo et al., 1995; Trotman, Hughes, & Mollison, 1995). *Streptococcus pneumoniae*, the bacterium responsible for invasive pneumococcal disease, was also commonly identified among admissions for pneumonia in WA in 1988-1993 (Williams et al., 1997), and to Cairns Hospital in north Queensland in 1992 (Thompson, 1997).

The total number of deaths from acute respiratory infections (including pneumonia) among Indigenous children is low (and the rate is low by international standards), but they comprise a disproportionately high proportion of such deaths in Australia. The combined mortality data from WA, SA and the NT for 1991-1996 shows that, of 22 deaths from acute respiratory infections among children aged 0-9 years, 9 deaths (41%) were Indigenous children. The relatively low mortality from acute respiratory infections in Indigenous children, compared with the situation in developing countries, has been achieved at the cost of an extraordinarily high rate of hospitalisation (Hanna & Torzillo, 1991).

Asthma was not identified in the past as a major problem among Indigenous people, but recent evidence suggests that this is no longer the case – 19% of Indigenous people reported to the 1995 National Health Survey that asthma was a recent and/or long-term condition (Australian Bureau of Statistics, 1999).[30] The highest prevalence of reported asthma was among children aged 5-14 years, with 23% of Indigenous children and 19% of non-Indigenous children reporting it as a recent and/or long-term condition.

It is likely, however, that the prevalence of asthma differs between urban and rural/remote areas. A study in the early 1990s in two rural Indigenous communities in Cape York, Queensland and two in central Australia found no self-reported recent wheeze among children 5-7 years of age, and a prevalence of only 0.5% in children aged 8-12 years (Veale et al., 1996). Lower levels than documented by the 1995 National Health Survey were reported also for Indigenous children aged 5 to 18 years living in a community in remote northern WA: 5.4% for males and 8.9% for females (Bremner et al., 1998).

These relatively low levels for rural-living Indigenous children are reflected in hospitalisation figures for the NT. A retrospective review of admissions to the Royal Darwin Hospital for the period 1991-1997 found that the hospitalisation rate for asthma for children aged 1-9 years was 2.6 per 1,000 population for Indigenous children from rural areas, 4.7 for Indigenous children from urban areas, and 5.5 for non-Indigenous children (Whybourne, 1999). The contribution of asthma to the overall burden of disease was far less among Indigenous than non-Indigenous children: 6.5% of Indigenous admissions were due to asthma compared with 12.7% of non-Indigenous admissions.

The WA hospitalisation profile for asthma is markedly different from that in NT. Admission rates for asthma in WA in 1988-1993 were much higher than those for the NT, with those for Indigenous children particularly high (Williams et al., 1997). Admission rates were generally higher for Indigenous than for non-Indigenous children, and were higher for Indigenous people living in non-metropolitan areas than in the metropolitan area.

Recent developments

Immunisation has been explored for some time as a major strategy to reduce the impact of pneumococcal disease among Indigenous people, but uncertainty about vaccine efficacy delayed implementation of routine programs. Children under 2 years of age have a poor immune response to the 23-valent unconjugated vaccine, which has been found to offer protection for adults in populations with high rates of the disease (Forrest, McIntyre, & Burgess, 2000). The effectiveness of this unconjugated vaccine led to calls for the immunisation of all Indigenous people aged over 15 years living in rural and remote communities and with identifiable risk factors (Hanna, Gratten, Tiley, Brookes, & Bapty, 1997; Torzillo, 1997).

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[30] 11% of non-Indigenous people reported asthma as a recent and/or long-term condition.

Even prior to these calls, the NT and WA had initiated pneumococcal immunisation programs for some or all of their Indigenous populations (McIntyre et al., 2000). As part of their 'adults are at risk' program, the NT has had adult immunisation since 1994-1995. Project officers were employed in 1995 to promote and distribute free pneumococcal vaccine to Indigenous people aged 50 years or over, or with risk factors. It was estimated from vaccine distribution data that 50% of the target population was immunised. In WA, a number of regional pneumococcal immunisation programs have been conducted in the Pilbara and parts of Kimberley since 1986 (McIntyre et al., 2000). After initially targeting children aged 2-15 years, the programs were extended to adults aged 50 years or over (McIntyre et al., 2000). From the late 1990s, immunisation has been provided in far north Queensland to Indigenous adults aged over 50 years and to younger adults with risk factors (McIntyre et al., 2000).

In 1999, the Commonwealth initiated the National Indigenous Pneumococcal and Influenza Immunisation Program, which provides free pneumococcal and influenza vaccines (through Indigenous community-controlled health services, State/ Territory immunisation clinics and general practitioners) for Indigenous people aged 50 years or over, and at-risk Indigenous people between 15 and 49 years of age (Commonwealth Department of Health and Ageing, 2001).

The need for a vaccine for infants and young children has been recognised for many years, but only recently has the efficacy of a 7-valent conjugated vaccine been confirmed (Forrest et al., 2000; Torzillo & Gratten, 2000). The efficacy of this vaccine, and encouraging progress on 9-valent and 11-valent vaccines, offers great potential benefits for Indigenous children.

Following approval for its use in Australia, the 7-valent conjugated vaccine was made available in Australia as part of the Commonwealth's National Childhood Pneumococcal Immunisation Program (Commonwealth Department of Health and Aged Care, 2001a). The Program provides funds for the purchase of vaccine for all Indigenous children up to 2 years, and for Indigenous aged 24-59 months living in central Australia and other regions likely to have a very high incidence of pneumococcal infection (Commonwealth Department of Health and Aged Care, 2001b).

Achievements

As noted above, vaccination against pneumococcal disease offers great potential benefits for Indigenous children and at-risk adults, but the relatively recent introduction of systematic programs means that it is too early for substantial achievements to have been documented. It has been noted, however, that a reduction in the incidence of invasive pneumococcal disease in far north Queensland has been attributed to the introduction of vaccination for at-risk Indigenous adults (Forrest et al., 2000).

The introduction of the programs is, of course, an achievement in itself. Their introduction has relied on the combination of good quality evidence of the enormous impact of invasive pneumococcal disease among Indigenous populations and more systematic approaches to addressing Indigenous health disadvantages.

The availability of effective vaccines against pneumococcal disease provides the opportunity of making substantial progress against this disease, but the prospects for other respiratory conditions are less optimistic. Anecdotally, there have been reductions over the past 20 years or so in the impact of other respiratory infections in childhood. On the other hand, asthma appears to have emerged as a major problem for many Indigenous children and adults.

As with many other health conditions, the high morbidity and mortality in Indigenous people from respiratory conditions are directly related to their poor environmental and socio-economic conditions (Currie & Brewster, 2001). Achievement of substantial progress against disorders that are not preventable by vaccination is unlikely to occur without major advances in the underlying conditions experienced by many Indigenous people.

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Diabetes

Background

Diabetes is a chronic, metabolic condition in which the body does not produce enough insulin. Since insulin is a hormone that helps glucose move from the blood into the cells, the cells of diabetics cannot use the glucose normally and this causes the blood glucose level to rise (Commonwealth State Diabetes Forum, 1999). Diabetes is classified into three main types – type 1, type 2, and gestational diabetes mellitus (GDM) (Australian Indigenous Health*InfoNet*, 2001b). Type 2 diabetes is the most common form for both the Indigenous and non-Indigenous populations.

Indigenous Australians have been reported as having the fourth highest prevalence of diabetes in the world (McCarty, Zimmet, Dalton, Segal, & Welborn, 1996). Indigenous adults are two to four times more likely to develop type 2 diabetes than non-Indigenous people, and the diabetes prevalence within the Indigenous population is between 10% and 30% (Australian Indigenous Health*InfoNet*, 2001a; de Courten et al., 1998). The disease also occurs at younger ages among Indigenous than non-Indigenous people.

In 1995-1997, deaths from diabetes were nine times more common than expected for Indigenous males living in WA, SA and the NT, and 16 times more common for Indigenous females (Cunningham & Paradies, 2000). Australia-wide in 1997-98, hospitalisation rates for diabetes were around six times higher for Indigenous than non-Indigenous people (Cunningham & Beneforti, 2000).

The development of diabetes has been linked to a number of modifiable and non-modifiable risk factors. The most significant of these are age, obesity, inactivity, poor diet, and family history (Commonwealth State Diabetes Forum, 1999; McCarty et al., 1996). Another risk factor which has been suggested by a number of authors is the degree of adaptation of a population to a westernised lifestyle (Carter, Pugh, & Monterrosa, 1996; McCarty et al., 1996; Neel, 1962; O'Dea, 1991).

Diabetes and its complications pose a serious health issue among the Indigenous population (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). The complications of diabetes can affect the eyes, feet, kidneys, nervous system, cardiovascular and immune system (McCarty et al., 1996), making it a potentially serious disease.

It has been suggested that many Indigenous people are not aware of the lifestyle factors that contribute to the development of diabetes (Carter et al., 1996), and that Indigenous diabetics are not effectively managing their diabetes on a daily basis (Markey, Weeramanthri, & Guthridge, 1996). The latter, in particular, is serious, since ineffective management usually leads to a greater risk of complications. AHWs have increasingly stressed the need for education programs, especially targeting rural Indigenous communities, towards healthy eating in order to prevent or manage diabetes (Knight & Enalanga, 1991).

Achievements

Given the magnitude of the problem of diabetes among many Indigenous populations, it is not surprising that there is a considerable literature on the subject. However, much of that literature is largely descriptive – of the epidemiology or of programs. The literature on achievements is much more limited, and virtually non-existent on the area of health outcomes (in terms of changes in incidence and/or prevalence and mortality).

Reports about most programs include attention to diabetes prevention, screening, education and/or management, with many addressing more than one of these aspects. However, to simplify the presentation here, brief details of programs and their achievements have been provided only in the category that appears to be the dominant feature for individual programs.

Diabetes prevention

The Minjilang Good Food and Health Project involved the people of the Minjilang community (Top End of the NT). The community was encouraged to use both traditional and contemporary knowledge relating to food and nutrition (Humphrey, Japanangka, & Marrawal, 1998). Nutrition sessions were conducted for children at school, basic dietary messages were developed for use in adult education, and efforts were made to increase the provision of good quality 'target' foods within the store. There was a significant increase in the sale of fruit and vegetables and other nutritious foodstuffs (such as wholemeal bread), with an accompanying decrease in the consumption of sugar. Community members continued implementing some aspects of the program after the health workers left.

By focusing on sustainable methods of weight control in the Aboriginal community of Looma (Kimberley, WA), the Looma Diabetes Program aimed to prevent people from developing diabetes (Ellis, 1996). People were taught how to prepare and cook foods using low-fat cooking methods and tasting sessions were used to introduce new foods. More people in the community started to exercise, including bush hunting or walking and playing sports. The community members participated positively in the program and more people talked about health and had an awareness of what they can do to stop themselves or their children from getting diabetes.

The Strong Together Good Tucker Workshop was designed to increase the number of community-based nutrition initiatives and programs through a sharing of nutritional information with an emphasis in strengthening Indigenous cultural knowledge and organisation (Humphrey et al., 1998). The workshop took place over three days and was designed to address issues affecting the nutrition and health of Indigenous people, their families and communities. The workshop, which was attended by over 200 people (including AHWs, and community elders and leaders), identified the need for a community-based nutrition worker program. A program soon commenced in Katherine and was taken up in other regions of the NT.

A number of other programs developed in the NT and neighbouring areas of SA focussed on education in terms of diet management, diabetes management, and understanding of health in a culturally appropriate and acceptable manner[31] (Humphrey et al., 1998). The programs coupled a community development process with the formulation of locally appropriate food and nutrition policies. They were designed to encourage community cooperation and participation in the design of a food and nutrition policy, and in the running of community stores. The programs produced posters, trained AHWs as storytellers, and developed an extensively illustrated 'flip chart' offering information on the medical and nutritional aspects of diabetes for distribution and use within Aboriginal communities. Community-based nutrition workers were established within the communities. Evaluation found that the programs had a significant impact on general knowledge about healthy eating and on reducing the consumption of sugar (especially by not adding sugar to tea).

Screening for diabetes

Participants in the Ntaria Diabetes Project (central Australia) were tested for obesity, diabetes, impaired glucose tolerance, hypercholesterolaemia, and hypertriglyceridaemia, in order to identify the need for appropriate prevention programs (Knight, 1992). The project, which had a response rate of 88%, was successful in documenting the various illness categories present in the region, and identified strategies by which these health areas can be evaluated and managed (Knight, 1992).

The Australian Families Against Diabetes program identified the genetic basis of type 2 diabetes by ascertaining pedigrees of families with multiple affected members among Indigenous communities in south-east Queensland region (Shaw et al., 2000). Participation involved a questionnaire, medical examination, fasting blood test; and screening for hypertension, hyperlipidaemia, obesity, type 2 diabetes, and a blood sample obtained for DNA analysis. An associated education program was coordinated through the community's school to provide lifestyle, diet, and exercise advice to reduce the risk of developing Type 2 diabetes in adult life. It is expected that improved understanding of the genetic basis of

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[31] Programs include the Diabetes Story Project, the Ernabella Non-Communicable Diseases Project, the Mutitjulu Mai Wiru Project, the Northern Territory: Flip Chart and the Store Book Project.

susceptibility to type 2 diabetes will facilitate the development of novel more effective approaches to diabetes prevention and treatment.

Diabetes education

The program 'Cooking Classes for Nyoongar People with Diabetes' conducted cooking/education sessions for rural Nyoongar diabetics in WA. Diabetics (and their carers) were taught how to prepare simple nutritious inexpensive meals in a culturally appropriate way (Wallent, Cook, & Bolton, 1995). On completion of the program, participants reported having to hide food from the children so that other family members could have some. There were requests to run further classes, and some Nyoongar men enrolled in cooking classes through TAFE.

The Alice Springs Hospital's 'Education Program for Aboriginal People with Diabetes' improved participants' diet, physical activity, and encouraged compliance with the prescribed medication of diabetic patients by quality education (Scrimgeour & Goscombe, 1993). Based on a questionnaire, it was confirmed that educational messages are remembered by patients. Behavioural change was far more likely if there was continuing contact among diabetics in their own communities. AHWs play a significant role in this regard.

The Aboriginal Diabetes Group helped to achieve a better understanding and control of diabetes among the Aboriginal people in the north-west suburbs of Adelaide (Centre for Health Equity Training Research and Evaluation, 1999)[32]. Patients who attended the Parks Community Health Service were invited to attend fortnightly lunchtime diabetes programs involving the preparation of a healthy meal and the opportunity to talk about issues related to diabetes. The program had immediate effects in promoting access to mainstream health services for the local Aboriginal community, as a number of people who participated in the group subsequently made appointments to meet with GPs to discuss their health. The involvement of family members in diabetes care was seen as a key strategy for successful self-management of diabetes in the Aboriginal community. The program found that the Aboriginal community approached issues in a holistic way, and, if interventions are to be successful, health must be considered in connection with socioeconomic and psychological concerns. It is understood that South Australian health authorities have now taken on this program.

A program based in Balranald (NSW) aimed to educate local Koori populations in managing their own diabetes through dietary education (Centre for Health Equity Training Research and Evaluation, 1999). These populations were educated in the use of glucose meters, and were provided with information on the long-term complications of the disease. The reluctance of Koori participants to write down information necessitated the use of simple, clear language so that all concepts and management strategies could be explained, repeated and understood verbally. Weekly group meetings enabled participants to have their health monitored regularly by the team (transport was provided), and two information sessions were provided by specialist care providers. Evaluation confirmed the improved understanding of participants about diet, exercise, eye and foot care and about the relationship of activity and diet to blood sugar levels.

The 'Diabetes in Aborigines: Avoidance and Control Program' provided health promotion information on diabetes to Aboriginal communities in the South Coast, Southern Tablelands and Monaro districts of NSW (Centre for Health Equity Training Research and Evaluation, 1999). Education was provided about diabetes prevention, management (including integrated management plans), and screening for complications. The program developed and distributed some culturally appropriate material (pamphlets, flyers and a poster), and a Diabetes Resource Kit for use by AHWs. As well as increasing awareness of diabetes among Aboriginal people, the program improved access to high quality primary care services.

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[32] More details of this project and a number of others documented by the Centre for Health Equity Training Research and Evaluation are available as case studies in the diabetes section of the Australian Indigenous Health*InfoNet* (http://www.healthinfonet.ecu.edu.au/).

Diabetes management

A program developed with Kooris of the Rumbalara community in Goulburn Valley (Victoria) helped to improve access to mainstream health care services and high quality diabetes care (Centre for Health Equity Training Research and Evaluation, 1999). A cultural awareness day for GPs was held at Rumbalara, and a process of up-skilling GPs who work in the area of Koori health was initiated. GPs have since given presentations to members of the Aboriginal community on various aspects of health care. Also, a Women's Health Clinic was established, and the development of locally relevant diabetic management guidelines was initiated.

The Living with Diabetes program developed and trialed an appropriate diabetes questionnaire in order to address culturally and socially appropriate aspects of diabetes care and its complications among Kooris living in Melbourne (Thompson & Thorpe, 1998). As well as contributing to the ways in which Kooris deal with the impact of diabetes on their lives, development of the questionnaire improved the research skills of local Koori researchers (Thompson & Thorpe, 1998).

A collaborative project involving the Port Macquarie Division of General Practice, Durri Aboriginal Corporation Medical Service, and the Mid North Coast Health Service addressed diabetes prevention and care for Indigenous people living in the Port Macquarie region of NSW (Centre for Health Equity Training Research and Evaluation, 1999). Through education and training of GPs and allied health professionals, standardised management of diabetes was promoted. A number of successful clinics have been run, and three- to four-day diabetes camps are conducted annually. A diabetes complications game has been developed, and diabetes literature and brochures have been 'personalised'. Durri provides diabetes talks at schools and TAFE in conjunction with a GP, and has developed 'outreach' clinics to outlying communities. Early data suggest that the project has resulted in a decrease in the prevalence of diabetes and a 15% reduction in the number of Aboriginal people with diabetes being admitted to hospital.

Improved management of diabetes was the aim of a culturally appropriate service for the estimated 700 Aboriginal people living in Port Lincoln (SA) (Centre for Health Equity Training Research and Evaluation, 1999). Guided by an advisory committee, a range of strategies was introduced in order to provide patients with flexible access to services and education. A home/community based service was developed and two diabetes camps were held. Podiatry, ophthalmology and dietetics services were provided through clinics. Training in diabetes was provided for AHWs, and discussions about diabetes undertaken at community meetings. The project increased the number of Aboriginal people who were comfortable attending formal clinics and appointments.

The Diabetic Foot Care program in the NT led to the development of a culturally appropriate foot care education tool – in the form of a flip-chart picture book – to be used by health-care professionals and clients in urban, community, rural and remote areas (Watson, Obersteller, Rennie, & Whitbread, 2001). The participatory action research process used in the tool's development ensured its ownership by Indigenous people and health-care professionals.

Summary

The best evidence of achievement in the area of diabetes among Indigenous people would involve documentation of decreases in incidence and prevalence of the disease and its complications, and a decline in mortality from diabetes. Even in the absence of such evidence, progress can be achieved in 'upstream' factors, such as increasing attention to the disease, greater awareness and understanding among Indigenous people of the disease, its risk factors and complications, and the development of more appropriate and more accessible preventive and care services.

The above summaries provide evidence of progress with these 'upstream' factors. There is no doubt that much has been achieved in the areas of diabetes prevention, screening, diabetes education and diabetes management across Australia. Detailed information on many of these programs is limited, and most have not undergone formal evaluation. Further, some were projects, in fact, rather than programs, and it has been beyond the scope of this review to investigate whether they have been sustained or not. In view of the potential value of sharing information about successful projects and programs, there is clearly a need for better knowledge management in the area of diabetes among Indigenous people. This need, of course, applies to all areas of Indigenous health.

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Renal disease

Background

End-stage renal disease (ESRD) occupies a prominent place in the current Indigenous epidemic of chronic disease, accounting for much of the renal morbidity and mortality seen in Australia's Indigenous communities (Hoy, Rees, Kile, & Norman, n.d.). Levels are highest in northern Australian communities, where the incidence of renal failure among Indigenous Australians has reached 'epidemic proportions' (Hoy, 1996) and, in recent years, has reportedly doubled every four years (Spencer, Silva, Snelling, & Hoy, 1998). In the NT, the vast majority of dialysis patients are Indigenous[33] (Hoy, 1996; Hoy, 1998), and treatment rates are increasing at such an alarming rate (Margetts & Morris, 1998, cited in Spencer et al., 1998) that the Territory's dialysis centres can scarcely meet the demand (Spencer et al., 1998). The numbers of Indigenous deaths attributed to renal disease are estimated to have increased 15 to 30-fold (Hoy et al., 2001b).

Increasing rates of ESRD among Indigenous people reflect the operation of multiple biopsychosocial risk factors (Spencer et al., 1998). The full spectrum of risk factors has yet to be identified (Menzies School of Health Research, 1999), but suggested factors include: increasing age, low birthweight and infant malnutrition, adult weight gain and the signs of Syndrome X (increasing blood pressure, insulin, blood glucose and lipid levels), skin infections, post-streptococcal glomerulonephritis, heavy drinking, repeated pregnancies and a family history of renal disease (Hoy, Vanbuynder, Mathews, Pugsley, & Wang, 2001a).

These risk factors are intimately related to the poor socioeconomic conditions that underlie the high burden of disease suffered by Indigenous people generally. Socioeconomic dimensions of the epidemic are considered to be at the root of burgeoning rates of ESRD, they include: the substitution of traditional hunter-gatherer and semi-nomadic ways with a sedentary Western lifestyle; unhealthy dietary practices; reduced activity levels; overcrowded substandard housing; high levels of tobacco and alcohol consumption; and community and cultural disruptions frequently associated with Indigenous populations in western societies (Hoy, 1998; Hoy et al., 1998).

The prevalence of risk factors for renal disease in Indigenous communities has implications for the demographic profile of Indigenous ESRD patients. ESRD in Indigenous Australians is more likely to present acutely, at a younger age than in the non-Indigenous population (in their 30s and 40s rather than their 50s and 60s), and more frequently among women (Hoy, 1996; Hoy, Mathews, & Pugsley, 1995; Spencer et al., 1998; Thomas, 1998). Indigenous patients are also more likely to present with various co-morbid conditions, including diabetes, hypertension, infections and poor nutrition (Hoy, 1996). The serious co-morbid conditions, coupled with high-risk behaviours (such as heavy smoking and drinking) and inadequate compliance, magnify the problem, complicating treatment and reducing survival rates (Hoy, 1996). Despite the age differences, the survival rates

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[33] Figures from the latter half of the 1990s indicate the number to be more than 95% of all dialysis patients (Hoy, 1998).

for Indigenous ESRD patients are often markedly lower than those for non-Indigenous patients (Spencer et al., 1998).

Achievements in our understanding of the epidemiology and treatment of ESRD among Indigenous Australians

Over the past decade there has been significant research into the causes, consequences and management of ESRD in the Indigenous population. The research is, in itself, an achievement, and has been important in the development of various prevention and treatment programs, among them a Menzies School of Health Research (MSHR) initiative implemented in the Tiwi Islands (off the coast of the NT). Ongoing research and screening led to the development of the systematic treatment program which has unequivocally demonstrated that renal disease can be easily diagnosed and its progression dramatically altered by interventions (Hoy et al., 2001a).

Tiwi Islands renal program

The beginnings of the Tiwi program can be traced back to the late 1980s when the MSHR initiated a community-wide screening program, partly in response to a request from the Tiwi Land Council 'to find out the cause of kidney failure in our people and do something about it' (Menzies School of Health Research, 1999, p.62).

In 1995, the MSHR and Territory Health Services, in consultation with the Tiwi Health Council, introduced the renal program (Commonwealth Department of Health and Aged Care, 2001). The program focused on vigorous blood pressure control and better metabolic management for people with diabetes and renal disease or with diabetes and high blood pressure. It was centred on the use of the long-acting angiotensin converting enzyme inhibitor, (ACEi) perindopril, an anti-hypertensive with cardiovascular and renal protective effects (Menzies School of Health Research, 2000).

By the end of 1998, 258 people had enrolled in the program (29% of all adults in the island communities) and 227 were still participating (Hoy, Baker, Kelly, & Wang, 2000). Participation was enthusiastic and compliance good in 70% of participants ((Kelly, Tipiloura, Hoy, & al., 1999) cited in (Hoy et al., 2001a)). An early evaluation of the health outcomes of the program indicates that it has: slowed the progression of renal disease; postponed renal failure; reduced premature death; averted much cardiovascular morbidity; and diminished associated health care costs (Hoy et al., 1999; Hoy et al., 2000). Evaluation suggests that progression to end-stage renal failure has been reduced by half and that there has been a reduction in deaths from natural causes. This has led to a reversal in the pattern of ESRD in the community, with previously increasing rates of ESRD and natural death reduced (Hoy et al., 2000). In the 1999-2000 annual report, the MSHR reported that no Tiwi person had started dialysis in the preceding 18 months, down from a peak of five per year in 1994-1995 (Menzies School of Health Research, 2000).

It is estimated that the Tiwi program saved between $700 000 and $3.1 million[34] in dialysis costs alone in its first three years (Hoy et al., 2001a).

The success of the program has been attributed to a strong sense of community involvement and a partnership approach between the health workforce delivering the program and the community. Specific facets of the program thought to have contributed to its success include:

- maximum involvement of local workers;
- a community-based rather than clinic-based focus;
- a collaborative, non-authoritarian approach;
- involving participants in their own testing;
- personalising health goals; and
- providing information not directives (Menzies School of Health Research, 1999).

The program demonstrated clearly that Indigenous people are interested in health issues and receptive to health messages (Hoy et al., 2000). Their willingness to participate enthusiastically and effectively in the long-term management of chronic disease has led to demonstrable improvements in their renal health. The Tiwi model has shown also that huge savings, in terms of

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[34] The savings depend on whether ESRD and death rates would have continued to escalate or achieved a plateau in the absence of the program intervention (Hoy et al., 2001a).

both premature death and cost, are achievable if investments are made in community-based strategies for kidney disease: in prevention; for early diagnosis; and for vigorous treatment when the disease occurs (to retard its progression to kidney failure) (Menzies School of Health Research, 2000).

The recognised success of the Tiwi program has led to the initiation of an outreach program that will work closely with Territory Health Services and independent Indigenous health care organisations to extend the principles of heightened awareness and better management of chronic diseases to other Indigenous communities. Evaluation will be an essential component of the program (Menzies School of Health Research, 2000). The program also forms the basis for projects initiated elsewhere. In SA, facets of the program have been replicated in the Umoona Kidney Project.

Umoona kidney project

The Umoona kidney project was initiated in response to a request from the Director of the Umoona Tjutagku Health Service (UTHS) (Shephard, n.d.). The Renal Unit at Flinders Medical Centre, in partnership with the UTHS, implemented the project to detect and prevent renal disease in the Aboriginal community of Umoona at Coober Pedy (in northern SA). The program began screening and treating adults in 1998 following 6 months of community liaison. Later the same year, at the request of the Umoona Community, the Renal Unit from the Women's and Children's Hospital in Adelaide joined the Flinders team. The aim was to provide an integrated renal health screening service for families of the 500-strong Umoona Community. Screening of children began late in 1998, with strong support from the UTHS and the Coober Pedy Area School.

The Umoona kidney project was owned by the Umoona community, directed by the Board of the UTHS, and managed by a Project Advisory Group that includes members of the Umoona community (Shephard, n.d.).

The project involved:

- screening of community members for risk factors for renal, cardiovascular and diabetic disease. Screening included the use of a simple instrument to measure the urinary albumin/creatinine ratio (ACR) to detect early renal disease (Shephard, n.d.; Shephard, Barratt, & Simpson-Lyttle, n.d.-a);
- treatment with an ACE inhibitor for those at risk (Shephard et al., n.d.-a); and
- a series of community-driven health education initiatives to address underlying risk factors, including nutrition and hygiene. The aim was to improve diet and reduce infection rates. Continuing education and training sessions in renal disease were also provided to Umoona's Aboriginal health care workers (Shephard, n.d.; Shephard et al., n.d.-b).

Within a year of its inception, 138 adult members of the community (mean age 42 years; age range 18 to 79 years) had been screened for their risk factor profile for renal disease and 38 had commenced medication (ACEi) (Shephard et al., n.d.-b).

Treatment options for people with ESRD

The Tiwi and Umoona projects offer primary, secondary and tertiary prevention measures designed to intervene in the disease process before individuals progress to ESRD. Measures of a different kind will be required, however, for those already afflicted with ESRD.

Without medical intervention, individuals with ESRD may die within weeks. Current treatment options to prolong the lives of ESRD patients require either a kidney transplant or regular dialysis to mechanically filter the blood. Kidney transplants are usually the best option, in terms of both medical outcomes and cost effectiveness (Thomas, 1998). However, the opportunities for transplantation within the Indigenous population are limited by difficulties associated with service delivery and a lack of compatible donors, and problems posed by infections or poor compliance (Spencer et al., 1998; Thomas, 1998).

Dialysis, specifically haemodialysis conducted in urban or regional clinics and hospitals, is the most common form of treatment for Indigenous Australians with ESRD[35] (Hoy, 1996), but is

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[35] Only 9% of Aboriginal patients entering the Darwin-based treatment program between 1993 and 1996 were treated with chronic ambulatory peritoneal dialysis (Spencer et al., 1998).

typically associated with high rates of withdrawal from treatment and low survival rates for those who continue treatment (Spencer et al., 1998). Poor treatment outcomes in the NT have been attributed to difficulties with chronic disability, the complex treatment regimen, and the loss of social support and connection with the land that accompanies relocation (Spencer et al., 1998).

Self-care dialysis in remote communities

In a bid to address poor treatment outcomes associated with relocation for clinic- or hospital-based haemodialysis, efforts have been made to deliver self-care dialysis services close to, or in, the home. This means that Indigenous people remain in their own communities, with their own family and social supports, and the costs of re-housing and supporting relocated dialysis patients are avoided (Kimberley Aboriginal Medical Services Council, 2000).

The challenge of delivering self-care dialysis in remote communities has been successfully met by a number of nephrology units around Australia (Thomas, 1998), among them the Western Australian renal program based at the Royal Perth Hospital. The RPH rural and remote area renal program was initiated in the late 1980s (Devitt & McMasters, 1998), when a multi-disciplinary group from the renal unit held discussions with local community leaders, medical, nursing and community health staff in the north of the State. This led to the development of a flexible program of care capable of accommodating individual variations, desired mode of treatment, cultural factors and the capacities of local facilities and staff (Thomas, 1993).

Since 1989, chronic ambulatory peritoneal dialysis (CAPD) and self-care haemodialysis have been delivered in areas up to 3,500 km away from the parent nephrology unit (Thomas, 1998). These nephrology units boast complication and dialysis survival rates that approach, and are sometimes better, those observed in urban dialysis units treating non-Indigenous populations ((Feutrill, Thomas, Lazberger, & al, 1996) cited in (Thomas, 1998)). Remote-area dialysis is still 25% more expensive than metropolitan self-care dialysis, but, when one takes account of re-location expenses, the overall cost is around half of that involving relocation of patients to the city (Thomas, 1998).

Self-care dialysis in remote communities provides an effective alternative to metropolitan-based treatment. However, when this option is not available or not practicable, remote-area patients are relocated to dialysis units in major cities, with significant biopsychosocial and economic consequences for both the individuals and the health care system (Thomas, 1998).

Relocation to metropolitan dialysis facilities

In recent years, increasing attention has been directed to the social implications of renal disease for Indigenous Australians. A joint study by the Central Australian Aboriginal Congress and the Menzies School of Health Research (Devitt & McMasters, 1998) is notable for its investigation of the social and cultural complexities that accompany the relocation and treatment of ESRD among Aboriginal people in central Australia.

The research documented the enormous social, cultural, geographical and physical difficulties experienced by Indigenous renal patients who, for the most part, relocated to Alice Springs from remote central Australian communities of just several hundred people (Devitt & McMasters, 1998). The socio-cultural alienation and isolation reported by the study participants was extreme, debilitating and ultimately life-threatening. The study provided irrefutable evidence of the urgent need for comprehensive health care that encompassed both socio-culturally responsive medical care and preventive measures.

In 1998, John Liddle, then Director of the Central Australian Aboriginal Congress described the study thus: 'One of the great strengths of this research was that it took a holistic approach, examining the social, cultural, and physical effects of renal disease, rather than just the narrow medical consequences. Its main features are that it was instigated by the Aboriginal community themselves to address a health problem that was identified by the community; that, being carried out through Congress, it remained under the control of the Aboriginal community during its course; that it passed on significant skills to Aboriginal people; and that it has led to practical action, through the newly created Renal Forum, to address the health problems of our people' (Devitt & McMasters, 1998).

The impact of the collaborative approach to service provision initiated in the central Australian project has subsequently been evaluated (Commonwealth Department of Health and Aged Care, 2001). The evaluation demonstrates that the capacities of secondary and tertiary health services may be improved by collaborative planning across service sectors. Multi-disciplinary case management processes can be used to address client needs effectively when multiple agencies are involved.

Research initiatives

The research and treatment initiatives associated with the Tiwi program have been widely documented and are among the best known of MSHR activities. A facet of the program that hasn't been mentioned previously, but constitutes a significant achievement, is the development of the Tiwi Legal Agreement.

In October 1998, the Menzies School of Health Research and the Tiwi Health Board signed an historic legal agreement providing for an ongoing research partnership with the Tiwi people (Menzies School of Health Research, 1999). The agreement provides the Tiwi with the right to exercise control over the research process. It also stipulates respect for cultural beliefs and gives legal force to the protection of Tiwi people as research participants. The agreement provides greater ethical protection than that provided under NHMRC guidelines.

A range of other research projects initiated by the MSHR have set out to clarify in greater detail the emerging picture of renal disease in Indigenous Australians by:

- enumerating rates, distribution and trends;
- defining causes, associations and morphology; and
- modelling and supporting strategies for its prevention, early diagnosis and treatment (Menzies School of Health Research, 1999).

Many of these initiatives have involved cross-disciplinary collaborations with other agencies, maximising productivity and leading to much broader findings (Menzies School of Health Research, 1999). Among the MSHR's collaborative partners is the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) which has, over the past 30 years, led the world in providing detailed epidemiological data on ESRD in Australian and New Zealand (Briganti, Knight, Atkins, & McNeil, 1999). Elucidation of the epidemiology of ESRD is, in itself, an achievement and forms the foundation for ongoing efforts to design effective prevention and treatment programs.

ANZDATA has recently been involved in one such epidemiological research project. The project sets out to determine regional patterns in the incidence of ESRD among Indigenous Australians (Cass, Cunningham, Wang, & Hoy, 2001). It also examines the availability of ESRD treatment facilities. The better definition of regional rates and trends of ESRD in Indigenous people and of the problems associated with access to treatment, as identified by the project, should facilitate rational resource planning and appropriate funding policies for treatment programs in all States and Territories.

This project is one of a number of MSHR initiatives that are epidemiological in design and contribute to a growing body of evidence describing the patterns of ESRD in Indigenous Australians.

Other notable MSHR research initiatives currently under-way include the first study to delineate the natural history of renal disease in Indigenous people, and determinants of its progression. Empirical evidence clearly demonstrates that the aetiology of renal disease is complex, multi-determinant and intimately linked to other chronic diseases (Menzies School of Health Research, 1999). A more definitive articulation of the aetiology will allow the evaluation of changes in disease behaviour over time, and the effects of interventions (Menzies School of Health Research, 2000).

Various other projects are:

- evaluating the association of various infections with chronic renal disease and cardiovascular disease;
- analysing kidney size, structure and function;

- exploring the relationships between the high rates of renal and cardiovascular disease in Aboriginal communities in the Top End; and
- examining the social and economic determinants of chronic renal failure in Indigenous Australians (Menzies School of Health Research, 2000).

Summary

A growing body of evidence from renal research and treatment projects demonstrates that some achievements have occurred, but highlights, too, the gaps in the current health care approach. Consideration of the evidence as a whole provides clear guidance for the way forward.

Increasing rates of ESRD, the negative social consequences that accompany treatment, and the high cost of tertiary level medical care all illustrate the immediate need for a comprehensive approach that addresses both the medical and socioeconomic dimensions of this growing problem. Primary prevention of the social and economic conditions that underlie much of the Indigenous health burden is a fundamental priority, but secondary and tertiary measures (such as screening and pharmacological interventions) also promise to reduce the risk of serious renal disease. Screening for renal disease can now be accomplished with simple, cheap and reliable techniques. Screening instruments may be readily incorporated within existing chronic disease screening protocols and coupled with proven interventions that modify the disease process (Couzos & Murray, 1999; Hoy, 1996; Thomas, 1998).

Indigenous renal patients require effective, acceptable treatment. The current emphasis on complex, expensive, often problematic, hospital-based treatment should be balanced with comprehensive, community-based, preventive action to minimise the underlying causes of the problem (Devitt & McMasters, 1998; Hoy, 1998; Hoy et al., 1999; Spencer et al., 1998). Prevention of the socioeconomic antecedents of renal disease is inherent in such an approach, which calls for:

- sustained improvements in living and environmental conditions, education, infrastructure and health services;
- implementation of integrated, effective and well resourced primary health care programs;
- primary health care measures to improve diet, control blood pressure and infections, maintain healthy adult weight, and increase birth weight;
- systematic screening for early and established renal disease; and
- pharmacological intervention programs to slow disease progress (Hoy, 1998; Hoy et al., 1999; Moore, Lloyd, Pugsley, & Seymour, 1996; Spencer et al., 1998; Thomas, 1998).

Regular evaluation is also a necessary component of any health program. Particularly for the Indigenous population, local ownership and management of health strategies is vitally important (Hoy, 1996).

The added advantage of comprehensive action is that it will reduce not just renal disease but also other chronic and communicable conditions that underlie the excess mortality observed in much of the Indigenous population (Spencer et al., 1998). Researchers argue that it is within the capabilities of integrated socioeconomic and public health initiatives to quickly reduce renal risk, and modify the existing disease profile, with potential savings in mortality and health care costs (Hoy, 1998; Hoy et al., 1999).

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Cervical cancer

Background

Cervical cancer is a major health issue for many Indigenous women. Overall, Indigenous women are twice as likely than non-Indigenous women to develop cervical cancer, and do so at younger ages (Kirk, Hoban, Dunne, & Manderson, 1999). Indigenous women are much more likely than non-Indigenous women to die from cervical cancer (Hunt, Gless, & Straton, 1998). Compared with non-Indigenous women, the risk of death from cervical cancer for Indigenous women is 4.3 times higher in major urban areas, 9.7 times higher in rural areas, and 18 times higher in remote areas (O'Brien, Bailie, & Jelfs, 2000).

The Papanicolaou smear (Pap) is the only effective and practical screening method for detecting cancer and pre-cancerous conditions of the cervix. Effective Pap screening programs can reduce mortality and morbidity by early detection and management of abnormalities in cells lining the cervix (d'Espaignet, Measey, Condon, Jelfs, & Demspey, 1996; Kirk et al., 1999; Mak & Straton, 1993), and the lack of such programs for the Indigenous population is thought to be mainly responsible for the high death rates (Mak & Straton, 1993). Generally, the main challenges for successful Pap smear screening involve maintaining smear frequency and targeting women in high-risk groups for cervical cancer (Couzos, Wribsjum, Murray, & Cox, 1998).

Indigenous women are far less likely to attend regularly for Pap smear tests than non-Indigenous women (O'Brien et al., 2000), and it is likely that perceptions of the procedure among the two groups differ markedly (Thurecht, 2000). It is believed that the Indigenous concept of health may play a part in this regard. Indigenous women's concept of health is much more broadly interpreted than the 'western' biomedical understanding of health. For many Indigenous women, good health is about wellbeing – physical, spiritual and emotional. Health is dependent on a balance of the physical and social environment (Kirk et al., 1999).

Indigenous women in rural regions and communities are most likely not to have Pap smears taken, and are the least educated about cervical cancer issues (O'Brien et al., 2000). This is due partly to the fact that there are less support services, screenings and follow-ups in rural areas than in urban areas (Hunt et al., 1998).

Achievements

Secondary prevention programs, which formed the majority of programs, generally focussed on the community as well as targeting the efficiency and quality of existing screening services (Hunt et al., 1998). The community focus directed attention to needs, patient satisfaction, and the presentation of this information for policy readjustment. These were successful in the short-term, but doubts were expressed as to whether these programs were sustainable in the long-term (Hunt et al., 1998). For further success and development to take place in the area of secondary prevention, more attention needs to be placed on the sustainability of the program. Since these programs were generally at the community level (although not community operated), more time would have been allocated to ensuring that the women involved received the care and service that they required (Kirk et al., 1999).

Community education

The Danila Dilba Health Service conducted education sessions with rural Aboriginal women in the Darwin region. The women were educated about the seriousness of cervical cancer, and about the screening procedures involved (Hunt et al., 1998). On completion of the sessions, the increased enthusiasm of the women with regard to their own health resulted in the development of a formal reminder system, and the re-orientation of screening activities in the region. Increased promotion of cervical health also increased in the clinical and community setting (Hunt et al., 1998).

The Aboriginal Women's Business Pap Smear Project featured education sessions for women along the north coast of New South Wales (North Coast Public Health Unit, 1995). The emphasis during these sessions was on education about screening procedures. Time was given for trust to develop between the educators and the women attending. The education sessions were combined with clinical services, so that the women could attend a screening session conveniently after an education session. Attendance at the sessions and associated screenings was 17.5% (slightly better than the 16% expected). Reflecting this enthusiasm, culturally appropriate teaching and learning materials (such as videos and posters) were developed.

An ongoing program developed by Queensland Health was designed to increase community education and knowledge about the seriousness of cervical cancer screening (Angus, 1999). This program incorporated the whole community (including men), not just women. Adequate training and education of health personnel working with Indigenous communities in Queensland was paramount, in order to increase prevention education, follow-up care, monitoring, and evaluation. Achievements of the program include the development of specific services and programs for carers of women with cervical cancer, and of a strong and appropriate workforce for dealing with cervical cancer issues within the Indigenous community.

Screening up-take

The Broome Regional Aboriginal Medical Service developed a program using a computerised process tool to facilitate selective recruitment of high-risk women overdue for Pap smears (Couzos et al., 1998). Women enlisted were those aged older than 40 years, living in remote communities, and who were more than five years overdue for screening. AHWs later used this tool in a community-controlled health service situated in a remote area setting and found not only that the screening rates had increased, but also that women attending felt more at ease being screened by community members. The holistic approach of the program was widely accepted by the rural communities, as these communities did not favour 'disease focussed' programs.

Improving the quality of care in remote communities on the AP Lands was the focus of a program developed by the Nganampa Health Council, which worked with local women in the development of an integrated program (Reath, 1999). Based partly on an analysis of the effectiveness of screening and the efficiency of recall systems, the organisation of local clinics and health practices was optimised for the most efficient delivery of cervical cancer screening services.

The Fitzroy Valley Pap Smear Register and Cervical Screening Program, which was fully operational between 1989 and 1993, increased the awareness of cervical cancer for many of the women in the region (Mak & Straton, 1997; Toussaint, Mak, & Straton, 1998). With the aid of a population-based register, the program achieved two- to over four-fold increases in screening rates, with the largest increases in women aged 50 years and older. Screening rates fell after the departure in 1993 of the program coordinator, but rates were still above 1987-1988 levels for most age groups (Mak & Straton, 1997). Overall, the program was very successful in recruiting a large proportion of eligible women within a relative short time period. However, coverage was not sustained after a 'decline in the recall system owing to staffing and organisational change' (Mak & Straton, 1997, p.70).

The impact of the 'Women's Business Weeks' program and Pap smear register at the Wurli-Wurlijang health service in Katherine (NT) was confirmed with increases in the number of smears taken and in screening rates among women aged 20 to 69 years (Todd, 1996).

Royal Perth Hospital's Pap Attack program provided a hospital-based cervical screening service to female in-patients over 50 years of age (including Indigenous women), who were believed to be under-screened (Bosman & O'Neil, 1998). Health information about cervical cancer screening was provided to under-screened women, and training and information was provided to appropriate hospital staff. The staff was educated also about the importance of hospitals in the provision of opportunistic screening. High proportions of women having Pap smears had never had one before, and screening rates were high for Indigenous and rural women. The success of the project highlighted the potential of the hospital system to play a role in opportunistic screening of under-screened groups of women.

Culturally-appropriate programs

Based on an analysis of barriers to cervical cancer screening in Queensland, guidelines for the delivery of health care services to Indigenous women were developed (Kirk et al., 1999). In addition to issues relating to the general concept of health, the main barriers to screening were the issues of shame (particularly if the practitioner is male); fear of finding out they had cancer; family or community experience of cancer; concern about confidentiality; racist attitudes of non-Indigenous health staff; distrust of health service staff; and fear of medical jargon. The analysis resulted in the formation of six new cervical screening programs specifically targeting Aboriginal and Torres Strait Islander women. Also, trained women's health practitioners are now working as part of women's health programs. Service provision has increased, and follow-up procedures improved. The number of health services to Indigenous women in Queensland is limited, especially in rural and remote areas, but Indigenous women are accessing the available dedicated women's health programs.

Strategy development

A program organised by the Commonwealth and the Western Australian health authority developed the Noongar Cervical Screening Cancer Project (Williams, 1997). The current state of cervical screening, the extent of knowledge, and target groups were identified. The information gathered was presented to funding bodies, governments and AHMAC, and a strategic plan for the implementation of culturally appropriate education programs was developed. Implementation included specific education programs for Indigenous women aged 60-69 years.

Queensland Health is refining its cervical cancer screening strategy for Indigenous women (Queensland Health, n.d.). The draft revision has been reviewed by the project steering committee, and disseminated throughout Queensland for comment. Particular attention has been directed to the issue of services to remote areas.

Summary

As is the case with most health conditions, the best evidence of achievement in the area of cervical cancer among Indigenous people would involve documentation of decreases in incidence and mortality. Such decreases are likely to flow from greater awareness of the disease among Indigenous women, supported by successful screening and treatment programs. There is considerable evidence of achievements in the first two of these aspects in the programs summarised above. However, no evidence was found of achievement in the third aspect – treatment programs. Another matter of concern was the sustainability of some programs. The failure of the successful Fitzroy Valley program, for example, to sustain its excellent results following 'staffing and organisational change' is of particular concern for services in rural and remote parts of Australia.

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Breast cancer

Background

Cancer of the breast is the most common cancer among all Australian women (Australian Institute of Health and Welfare, 2000), and is likely also to be the most common cancer among Indigenous women (Coory, Thompson, & Ganguly, 2000; South Australian Cancer Registry, 1997; Thomson & Irvine, 2001). Information about mortality is less complete, but breast cancer was responsible for the most cancer deaths among Indigenous females in Western Australia in 1993-1997 (Thomson & Irvine, 2001).

The factors contributing to the development of breast cancer include: reproductive history (especially nulliparity/low parity, late age of first pregnancy early onset of menarche, late menopause, low breastfeeding frequency and duration); alcohol consumption; and inherited genetic factors.[36]

The data are variable, but mortality appears to be slightly higher among Indigenous women than expected from breast cancer incidence. This comparatively high mortality has been attributed to lower rates of participation in screening programs (resulting in later diagnosis) and differences in treatment (Carrick, Clapham, Paul, Plant, & Redman, 1996; Kirk et al., 2000). Among Indigenous women, 52% reported examining their breasts regularly, 57% reported ever having had their breasts examined by a health care professional, and 26% of

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[36] A number of genes are estimated to explain between 5-15% of all breast cancers among Australian females. There is no information currently available about the prevalence of these genes among Indigenous females, so the role of family history in breast cancer in Indigenous females is unknown (Thomson & Irvine, 2001).

eligible women aged between 50 and 69 years had received a screening mammogram in the previous two years (Carrick et al., 1996).

Achievements

As with many other areas of Indigenous health, the literature on breast cancer is sparse, and no reports of improved health outcomes (such as reduced incidence or mortality) or better health systems (such as improved screening rates) were located.[37]

Despite the lack of evidence of achievements in health outcomes and health systems, there is little doubt that the past decade has witnessed great advances in the awareness of breast cancer as an issue – by Indigenous women and by Indigenous and non-Indigenous health professionals. This is evidenced by the publication by the National Breast Cancer Centre of its major report, *Breast cancer and Aboriginal and Torres strait Islander women* (Carrick et al., 1996). As well as drawing national attention to the issue of breast cancer among Indigenous women, the report includes brief summaries of a variety of local initiatives, which demonstrate progress in raising the awareness of breast cancer among Indigenous women.

The greater attention being paid by cancer organisations and screening services to breast cancer among Indigenous women is evidenced by the Queensland Government's funding of specific research examining screening, diagnosis and treatment of the disease (Kirk et al., 2000).

It is likely that this greater attention and awareness will have contributed already to improvements, at least in screening, but evidence of such improvements was not located in this review.

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Ear disorders

Background

Otitis media is a common condition for many young children.[38] It is one of the most significant causes of hearing loss, but it is also one of the most preventable. Otitis media is a common condition among all Australian children, but Indigenous children are the most severely affected in Australia (Morris, 1998). Prevalence studies within the Aboriginal and Torres Strait Islander population suggest that the level of disease varies considerably, but a national survey found that

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[37] It is possible that some reports do exist - such as those produced by screening services - but the general nature of this literature review precluded the more intensive approach required to identify and collect this type of grey literature.

[38] See the Australian Indigenous Health*InfoNet* for an overview of ear diseases and their consequences.

15% of children under 10 years of age had a perforated eardrum (Australian Indigenous Health*InfoNet*, 2001a; Australian Indigenous Health*InfoNet*, 2001b; Morris, 1998). This prevalence is far higher than those categorised by the World Health Organisation as being 'high risk' (populations with chronic eardrum perforation rates greater than 4% are categorised as 'high risk' and greater than 10% as 'extremely high risk') (Morris, 1998). The need for greater monitoring for ear disease within Indigenous children was recognised by the House of Representatives Inquiry into Indigenous Health (House of Representatives Standing Committee on Family and Community Affairs, 2000).

The problem of ear disease among Indigenous children is complex with multiple contributing factors. These factors include poor hygiene, overcrowded housing and poor nutrition. An important implication of ear disease is its impact on speech and language development, which can limit a child's educational achievement, and contribute to ongoing problems (Higgins, 1997).

Recent developments

In recognition of the importance of ear disease, the National Aboriginal and Torres Strait Islander Hearing Strategy, specifically targeting children aged 0-5 years, has been implemented by the Commonwealth Department of Health and Aged Care (2001). The four components of the strategy provide for: funding of hearing programs through 29 Aboriginal community-controlled health services; the supply of audiometric equipment; training to Aboriginal Health Workers; and strategic research. One of the underlying goals of the strategy is to build 'strong partnerships between key stakeholders with the view to improving coordination and access to the full range of hearing services'.

As part of the strategy, *Recommendations for Clinical Care Guidelines on the Management of Otitis Media in Aboriginal and Torres Strait Islander Populations* outlines strategies and actions to be taken at all levels of prevention and treatment for otitis media (Menzies School of Health Research, 2001). These guidelines have been based on the best available primary research on otitis media and evidence-based clinical practice guidelines. The report recommends strategies on primary prevention of otitis media; diagnosis of otitis media; prognosis; management of otitis media at all stages; and the practical considerations in health care delivery.

These recommendations address the overall management of otitis media, but it has been noted that, to control the problem in the Indigenous population, the main prevention strategies required are environmental. These include the alleviation of housing and overcrowding problems, and availability and access to good nutrition (Couzos, Metcalf, & Murray, 1998).

Reflecting this, the NSW Health Department's *NSW Otitis Media Strategic Plan for Aboriginal Children* is based on a holistic view of Aboriginal health and 'recognises that the health of Aboriginal children in influenced by a broad range of family, social, educational, environmental, economic, cultural and biological factors' (NSW Health Department, 1998, p.1). This strategy calls for:

- a coordinated partnership between all stakeholders and service providers;
- accessible, available services that are delivered in a culturally appropriate manner;
- controlling otitis media and conductive hearing loss through screening, referral, and medical and audiological management strategies based on the clear protocols;
- educational support for Aboriginal children to be seen as an integral component of any otitis media program;
- community awareness and prevention;
- training in culturally sensitive methods and professional development for health professionals, which meet the needs of local Aboriginal communities; and
- monitoring, evaluation and research to assess the effectiveness of the plan (NSW Health Department, 1998).

Achievements

Available data suggest that the prevalence of otitis media has not been reduced among Indigenous children over the past decade or so. However, some successful programs have been implemented to treat existing cases of ear disorders and prevent the long-term complications associated with hearing loss. Also, considerable progress has been made in understanding of the extent and nature of the problem.

Research and studies conducted by the Menzies School of Health Research, for example, have been instrumental in highlighting the impact of ear disorders on education and the literacy capacity of Aboriginal children (Menzies School of Health Research, 2000). It is anticipated that the results of such studies will form the basis of future collaborative interventions between health and education professionals.[39]

Programs that have had a community focus and involved collaboration with other groups have also had positive outcomes. An example is an otitis media program implemented in Dajarra (Queensland), which saw the community as a whole working with the school, using a number of strategies to improve learning outcomes (Higgins, 1997). Overall, there was an improvement in the ear health of the students: of the 34 students identified with otitis media at the commencement of the project, 29 no longer had the same severity of the disease twelve months later.

A number of tertiary intervention programs have also had some success. The Aboriginal Ear Health Program, which ran between 1995-1997 in the communities of Maningrida, Bathurst Island and at the Regional Hospital in Katherine, involved myringoplasties to improve hearing acuity (Foreman, Vercoe, & Aithal, 1999). Patients accepted surgery more readily as it was carried out in their own community. Evaluation of the program was based on pre-operative and post-operative tests. Myringoplasties were performed on 54 patients, mostly teenagers. Eighty-seven per cent of patients at Bathurst Island and 80% of those of the Katherine Hospital had improved hearing acuity. However, reduced rates of perforation closures and high rates of partial closure were noted. It was suggested that difficulties – such as severe climate, poor hygiene, and poor nutrition, plus problems with treatment compliance and the reduced socioeconomic and education status of Aboriginal people in many isolated communities – may limit the effect of surgery compared with results for non-Indigenous children.

The antibiotic treatment of middle ear infections in Aboriginal infants has also seen some positive results. A randomised-controlled trial evaluating the efficacy of long-term administration of amoxycillin for the prevention of chronic otitis media found fewer perforated ear drums in the group receiving the antibiotic (Cooperative Research Centre for Aboriginal and Tropical Health, 2000).

Reports suggest that the best management of ear disease within the Indigenous population requires the partnership of community health workers and nurses, audiologists and medical personnel (Weeks & MacKendrick, 1996). This team ensures the primary detection and management, diagnosis and medical treatment or surgical intervention of ear disease.

A promising intervention has been initiated by the Education Department of WA in collaboration with the TVW Telethon Institute for Child Health, the Health Department of WA, the Perth Aboriginal Medical Service (now Derbarl Yerrigan) and the WA Institute for Deaf Education. This has seen the launch of a technology-driven tool to assist in the identification of and prevention of otitis media. The CD-ROM called *Do you hear what I hear* helps to identify and treat children with otitis media as early as possible. It is used by schools, parents, caregivers, health workers, speech pathologists, audiologists and other community members (Education Department of Western Australia, n.d.).

Summary

The literature provides some evidence of achievements in the area of ear health among Indigenous children, and strongly suggests that an inter-sectoral collaborative approach is required. Success has been achieved when partnerships have been established, but this appears be only in the secondary and tertiary prevention levels. Tertiary prevention programs need to consider contributing factors that may limit surgical results. These include the isolation of communities, climate, treatment compliance, poor hygiene and problems in general health. Achievements in

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[39] Much of the literature on otitis media addresses epidemiological and associated factors, and will not be discussed further here.

secondary and tertiary prevention are important, but the prevalence of otitis media will only be reduced when causal factors are addressed adequately from a primary prevention perspective.

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Eye disorders

Background

Impairment or loss of vision can result from the ageing process, diseases, injuries, vulnerability to risk factors, and genetic factors. The Melbourne Visual Impairment Project, conducted by Centre for Eye Research Australia (CERA) from 1991-1998, found that three-quarters of loss of vision in the Australian population was caused by five conditions; refractive error, glaucoma, macular degeneration, cataract and diabetic eye disease (Centre for Eye Research Australia Limited, 2000). Another potentially blinding condition, trachoma, is an eye disease found almost exclusively within the Indigenous population in Australia with a childhood prevalence of 20% or more in some communities (Office for Aboriginal and Torres Strait Islander Health, 2001). Apart from personal loss, vision problems can lead to dependence on others, an increase in use of community services, and a loss of input to the community. Many eye diseases can be prevented and interventions that relieve or prevent eye health problems have been demonstrated as being cost-effective.

The main eye conditions, and general details in regard to Indigenous people, are:

Refractive error

Urban Aboriginal and Torres Strait Islander populations have vision and refractive problems similar to the general population. Vision 2020 (see below) aims to provide access to ready-made reading glasses to Aboriginal communities through existing schemes and to review the effectiveness of visiting optometrist schemes in meeting refraction needs particularly in remote areas (Holden, 2000). Indigenous people may be eligible for low cost glasses, but access and utilisation seem poor due to in-built barriers in these schemes (Taylor, 1997). There is a significant unmet need for refractive services generally in Aboriginal communities, and access to and utilisation of low cost glasses in State and Territory schemes is poor.

Glaucoma

Glaucoma is a group of eye diseases, the most common form of which, open angle glaucoma, is related to ageing. The normal fluid pressure inside the eye progressively increases and, if untreated, can lead to vision loss. Glaucoma testing is a usual component of eye health checks for older people. There appears to be no Indigenous-specific information available in the literature on screening and treatment.

Age-related macular degeneration

Age-related macular degeneration (AMD) is a degenerative condition affecting the central area of the retina called the macula. The Cardiovascular Health and Age Related Maculopathy (CHARM) study is a three-year project which commenced in 2000 with funding from the NHMRC. The aim of the project is to quantify risk factors for age-related maculopathy, the leading cause of blindness in Australia (Centre for Eye Research Australia Limited, 2000). There appears to be little information available specifically for Indigenous populations.

Trachoma

Trachoma is a form of conjunctivitis caused by the bacterium *Chlamydia trachomatis*. Azithromycin is an effective therapy for trachoma although bacterial resistance to the medication has affected success rates. It can be used as a single dose, which is preferable to previous treatments that involved prolonged courses of tetracycline ointment, had poor compliance rates, and were relatively ineffective (Taylor, 1997).

Cataract

A cataract is an opacity of the crystalline lens of the eye, which develops progressively and prevents light from reaching the retina at the back of the eye. The risk of cataract increases with age and its occurrence doubles with each decade after the age of 40 years. Cataract surgery is the major eye surgery required by Indigenous people. Late presentation for treatment is often an issue, and can be related to concerns about moving away from the community for treatment.

Diabetic retinopathy

Diabetes is an increasing health problem for Indigenous people, and all people with diabetes are at risk of developing diabetic retinopathy (microvascular lesions of the retina). Early diagnosis and treatment are essential – regular screening can detect early stages of retinopathy and timely retinal laser treatment can prevent blindness. Computer-based patient management systems readily facilitate regular examination and retinal cameras allow health workers to perform eye screening (Taylor, 1997).

Recent developments

Training and support in ophthalmic and optometric eye care for Indigenous people in NSW has been supported by OATSIH in that State. It was announced in 2000 that seven Aboriginal Eye Health Coordinators would be trained through a collaborative approach with: the International Centre for Eye Care Education; the Department of Ophthalmology of the University of New South Wales at the Prince of Wales Hospital; and the Cooperative Research Centre for Eye Research and Technology. This was a response to reports that identified a lack of regional coordination and barriers to accessing effective eye care (such as: lack of eye health awareness; lack of support and follow-up; and social and economic conditions). In NSW, 82% of the available ophthalmologists are situated in the major urban areas of Sydney and Newcastle. This means that rural services, particularly to remote areas, are limited and available only intermittently. The tasks of the coordinators include improving the delivery of services to Aboriginal communities (Dimond, 2000).

The sharing of Indigenous specific eye health information has recently been a focus. The report*,* *Eye health in Aboriginal and Torres Strait communities* (Taylor, 1997), provided recommendations to address issues such as the status of eye health for Indigenous people and the provision of specialist eye services. In response, the Commonwealth Government committed itself to the implementation of a National Aboriginal and Torres Strait Islander Eye Health Program through OATSIH. As part of the implementation, OATSIH commissioned the CERA to develop, in collaboration with NACCHO, evidence-based clinical practice guidelines for the provision of specialist eye care. The guidelines, based on a review of existing literature and practice, provide information about the treatment and management of three eye health conditions, cataracts, diabetic retinopathy and trachoma (Office for Aboriginal and Torres Strait Islander Health, 2001).

Vision 2020: the Right to Sight, a global initiative, has targeted a number of the leading causes of avoidable blindness in Aboriginal and Torres Strait Islander communities (Holden, 2000). Aims include:

- performing cataract surgery routinely at regional level (the prevalence of cataract in the Indigenous population is 10 per 1,000 compared with 4.7 per 1,000 in the non-Indigenous population). At least 2,500 operations are needed per year to clear the backlog and to treat new cases;
- providing adequate screening programs for trachoma and supporting an integrated primary health approach to manage trachoma;
- providing access to ready–made reading glasses in Indigenous communities and improving access to low-cost glasses through existing schemes;
- reviewing the effectiveness of visiting optometrist schemes in meeting refraction needs, particularly in remote areas; and
- encouraging regular eye screening and appropriate regionally based equipment and training for the management of diabetic retinopathy.

Vision 2020 also aims to: increase awareness of blindness as a major health issue and control the major causes; train ophthalmologists and other eye care personnel to provide appropriate eye care; create an infrastructure to manage the problem and develop appropriate technology (Holden, 2000).

Achievements

Good eye health management includes regular screening by primary health services for eye diseases such as trachoma and diabetic retinopathy. Primary health services have an important role in monitoring eye health in communities and contributing to state and national surveillance systems. The provision of specialist eye services varies greatly across Australia. Several eye health models are used nationally with one of the best, according to Taylor (1997), provided through a regional public-private model, which combines public funding for infrastructure and hospital services with Medicare bulkbilling for specialist eye services. This model, which is used in the Pilbara and the Eastern Goldfields of WA and in Far North Queensland, ensures ongoing commitment from the private ophthalmologist and the health services within the region. The regional public–private model also provides services to outlying communities that are visited at least annually. The regional centre is used for cataract and laser surgery and more frequent patient review. Another initiative is the use of mobile eye units, which have been used by the NT Aboriginal Eye Health Committee to improve access to screening (Taylor, 1997).

Aboriginal community-controlled health services provide an important link in the search for better health outcomes in: providing eye health care services; maintaining patient records; providing support for patients and families; arranging transport, and liaising between the patient, medical officer and the regional hospital (Office for Aboriginal and Torres Strait Islander Health, 2001). They also assist patients in decision-making in considering whether the potential visual improvement outweighs the potential risk, cost and inconvenience of surgery.

Systematic screening for trachoma has led to positive outcomes. An example is the Kimberley Trachoma Control Program, initiated in 1991, which annually surveys school children. Prevalence of trachoma is reported to be declining (Thomson & Paterson, 1998).

Programs that address inadequate and unhygienic living conditions assist in preventing trachoma transmission. It is evident that improving basic services leads to improvements – as demonstrated in places such as Bourke and Broome, where trachoma has essentially disappeared (Taylor, 2001). Inflammatory trachoma remains endemic however in some remote communities of central Australia (Roden, 2000).

Progress against trachoma should benefit by the specialist eye health guidelines, the goals of which are to:

- identify the communities in which trachoma is present;
- enable the adoption of a consistent approach to the assessment and treatment of trachoma in those communities; and
- provide the framework for the implementation of 'best practice' in the management and treatment of trachoma (Office for Aboriginal and Torres Strait Islander Health, 2001).

Cataract surgery has become more available to Indigenous people. However, clearing backlogs, the constraints on the availability of ophthalmologists, and post-operative care are still matters for concern (Taylor, 1997). One approach to addressing the backlog among Aboriginal people in central Australia was the performance of cataract surgery by Australian Defence Forces from a mobile tent theatre in Alice Springs in 1994 (Thomson & Paterson, 1998).

An achievement in itself is the publication of the specialist eye health guidelines (Office for Aboriginal and Torres Strait Islander Health, 2001), a goal of which is to assist in achieving 'best practice' in the management of cataract and intra-ocular lens surgery in Aboriginal and Torres Strait Islander people, particularly those living in rural and remote regions where access to specialist eye health professionals and hospital care are limited. The aim of cataract surgery is to achieve a rapid, stable recovery of vision to the preferred refractive status with a minimal morbidity and risk. The guidelines are aimed at achieving goals that respect cultural differences and individual preferences and facilitate individual and community involvement.

The requirements to fulfil the goals are to:

- identify the presence of cataract and if present the impact on visual and functional status and quality of life;
- advise the patient about surgery, establish criteria for a successful treatment outcome with the patient; and
- perform surgery and follow-up treatment, if required (Office for Aboriginal and Torres Strait Islander Health, 2001).

The specialist eye health guidelines (Office for Aboriginal and Torres Strait Islander Health, 2001) recommend that blindness caused by the condition diabetic retinopathy can be prevented with appropriate screening, therefore regular eye examinations are needed. The goals for 'best practise' are to:

- identify Indigenous people at risk of the condition;
- educate and manage people with diabetes to prevent the complication of diabetic retinopathy; and
- provide laser treatment for those with the condition.

Summary

Generally, there have been improvements in Indigenous eye health in: the sharing of expertise; the employment of Indigenous health workers; the development of specialist eye health guidelines; the provision of funding and equipment to ensure better access to services (particularly in remote areas of Australia); the building of partnerships; and improvements in methodology and technology.

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Oral health

Background

Oral health is an important component of overall health. The consequences of poor oral health include pain, infection, impaired speech, interference with eating habits, and social embarrassment – all of which may significantly reduce an individual's quality of life (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001; Pacza, Steele, & Tennant, 2001). Risk factors for poor oral health include: low fluoride exposure; diets high in refined carbohydrates; smoking; alcohol consumption; stress; infection; reduced tooth brushing and flossing; infrequent dental visits; diabetes mellitus; malnutrition; and increasing age (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001; Martin-Iverson, Phatouros, & Tennant, 1999). Many of these factors are prevalent within Indigenous communities.

Oral health status among Indigenous Australians

As recently as the mid-1900s evidence suggested that Indigenous Australians from some remote communities had few oral health problems (Pacza et al., 2001). However, dietary changes associated with broader lifestyle modifications have had a marked effect on the oral health status of Indigenous Australians. Increased sugar consumption and decreased intake of proteins and vitamins has led to increased risk and prevalence of dental caries (tooth decay) and periodontal (gum) disease (Martin-Iverson et al., 1999).

Detailed information regarding their oral health is limited, but recent national surveys indicate that Indigenous people have poorer oral health outcomes than their non-Indigenous counterparts. Indigenous Australians had fewer dental visits, were more likely to visit services for a dental problem rather than a check-up, experienced more toothache, were less likely to have dental insurance, and were more likely to report difficulties paying a $100 dental bill (Brennan & Carter, 1998).

Some information regarding the oral health of Indigenous children in the NT is available from the Child Dental Health Survey. Comparative data reveal that Indigenous children are more likely to have decayed, missing or filled deciduous and permanent teeth than their non-Indigenous counterparts (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

The Commonwealth Dental Health Program, which ceased in 1996, and the National Dental Telephone Interview Surveys (conducted between 1994 and 1996) provide some data on the oral health of Indigenous adults. These data suggest that dental problems, tooth extraction and edentulism (the loss of all natural teeth) are more common among Indigenous adults than among their non-Indigenous counterparts (Brennan & Carter, 1998).

Access to dental services

The problem-oriented dental visiting patterns and higher extraction rates observed among Indigenous people are usually indicative of inadequate access and associated with a lack of comprehensive dental services. Access to adequate dental services is particularly problematic in rural and remote areas. The 1994 National Aboriginal and Torres Strait Islander Survey reported that only 46% of Indigenous Australians in rural areas had access to dental services (Australian Bureau of Statistics, 1994).

Limited access to modern dental services and the low natural fluoride levels in many rural and remote Indigenous communities place residents at increased risk of dental disease (Martin-Iverson et al., 1999). The current lack of specialist dental care within many communities suggests that an alternative approach to the oral health needs of Indigenous Australians in rural and remote communities is required. A recent submission by NACCHO to the Senate Community Affairs References Committee Inquiry into Public Dental Services recommended that 'Aboriginal health workers (AHWs) should be supported nationally to acquire dental knowledge, at the very least in oral health promotion, and even to the extent of being able to perform some basic dental procedures' (National Aboriginal Community Controlled Health Organisation, 1997).

Achievements

Few AHW training programs incorporate a significant oral health component (Pacza et al., 2001), and many rural and remote AHWs have little or no dental knowledge (National Aboriginal Community Controlled Health Organisation, 1997). However a recent initiative developed by the University of WA has set out to address this issue by developing an oral health training program that considers the unique training needs of rural and remote AHWs (Pacza et al., 2001). The program was piloted in a number of AHW training facilities in rural and remote areas of WA. Feedback indicated that the students found the training modules enjoyable and relevant to their needs. Almost all students considered that the modules facilitated a good understanding of the specific learning objectives. It is envisaged that AHWs who complete the program will acquire the skills necessary to implement long-term preventive measures to improve oral health in their communities.

Other efforts to address the oral health needs of Indigenous Australians in remote areas include the recent development by the Nganampa Health Council of a training manual *Dentistry in remote Aboriginal communities* (Nganampa Health Council, 2001). The manual is designed to assist dental personnel working in remote Aboriginal communities. It offers a cultural and clinical orientation to remote oral health programs, and provides information on primary health care and service delivery systems.

Summary

The poor oral health status of Indigenous Australians is widely acknowledged, but this review highlights the lack of comprehensive information and the absence of appropriate programmatic interventions. More research is required to assess the needs of Indigenous populations and develop appropriate oral health programs, but, as NACCHO points out, 'sound epidemiological data will be meaningless if there are no resources available to address the extent of the problems measured' (National Aboriginal Community Controlled Health Organisation, 1997).

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Anaemia

Background

The most common form of anaemia among Indigenous people (particularly children) is iron deficiency anaemia (IDA), which is much more prevalent in Indigenous than non-Indigenous Australians (National Health and Medical Research Council, 1999). IDA occurs when the amount of iron in the body is less than that required for normal formation of haemoglobin, iron enzymes, and other functioning iron compounds. IDA is characterised by red cells becoming smaller than normal and having low concentrations of haemoglobin. Iron deficiency remains the most common nutrient deficiency in the world (National Health and Medical Research Council, 1999).

There are numerous causes of iron deficiency, which can progress to IDA (National Health and Medical Research Council, 1999). Rapid growth in infancy imposes large iron needs and the bio-availability of iron in the infant diet is quite low, so inappropriate nutrition is likely to play a major role. In women of childbearing age, iron loss from pregnancy or heavy menstrual periods may, on a long-term basis, not be matched by dietary iron. In males and in post-menopausal women, the major cause of iron deficiency is pathological bleeding. This occurs most commonly from the gastrointestinal tract (for example, from peptic ulcers, gastritis, haemorrhoids, and tumours). Gastrointestinal bleeding can occur also from parasite infestation.

Hookworm infestations are present in some coastal and inland communities in the northern Kimberley region of WA (Hopkins et al., 1997), and are endemic in many communities in the NT (Kruske, Ruben, & Brewster, 1999; Prociv & Luke, 1995). Hookworm disease may manifest as IDA (resulting from gastrointestinal blood loss caused by worms attaching to the small intestine mucosa) (National Health and Medical Research Council, 1999). The total worm burden, the level of dietary iron intake, and the level of physiological iron loss influence the severity of anaemia. A survey of a community in the north of WA found that hookworm infestations were likely to contribute to the high prevalence of iron deficiency and anaemia, which were observed particularly in young children and women (Hopkins et al., 1997). Inadequate dietary iron intake contributed to the high levels of iron deficiency (50%), as 31% of women aged more than 14 years who were hookworm-negative had IDA.

Achievements

Despite the number of studies documenting the causes and effects of IDA in the Indigenous population, there have been few programs developed to lessen the burden of anaemia (Hopkins et al., 1997). The discussion here is restricted to three areas: professional and community awareness of anaemia as a problem, anaemia treatment, and hookworm control and eradication.

Awareness of anaemia

A workshop on anaemia in Indigenous children, run by the Miwatj Health Service at Nhulunbuy (NT) in June 2001, attracted participants from a number of remote communities (including Maningrida, Galiwin'ku, Numbulwar, Yirrkala, and Marngarr) (Nguyen, 2001). The three sessions provided an overview of anaemia, considered contributory factors, and discussed present or intended projects or programs. As well as generally raising the awareness of anaemia as a continuing problem, the workshop drew attention to the need for broad-based community approaches.

Anaemia treatment

The findings of a randomised unblinded clinical trial of treatment for anaemia among Aboriginal children living on a community in Arnhem Land provides the basis for committed programs to address the significant problem of IDA (Kruske et al., 1999). The most effective strategy to address nutritional problems in the weaning period, including IDA, would be a community-led nutritional intervention program with a high energy weaning food fortified with micronutrients (vitamin A, zinc, folate and twice-weekly iron).

Hookworm control and eradication

Recent research in a community in the Kimberley region of WA reports that hookworm has been effectively controlled with a regular therapeutic use of albendazole (an anti-helminthic agent), combined with continued health education and environmental management (Thomson, Reynoldson, Garrow, McCarthy, & Behnke, 2001). The research suggests that, with sustained control programs, hookworm could be eradicated from northern WA and the NT – as it was many years ago in Queensland (Prociv & Luke, 1995). However, while human hookworms persist anywhere in northern Australia, the infection could reappear and spread rapidly unless living conditions improve significantly (Prociv & Luke, 1995).

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6.4 Communicable diseases

Background

A communicable disease is one that can be spread from one person to another (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). Communicable diseases are classified generally into two categories – STIs (sexually transmissible infections) and those which are transmitted through contact with contaminated foods, air, water, etc. – but the distinction is not absolute (Somerford et al., 1995).

Surveillance of communicable diseases is a crucial component of public health strategies for their prevention and control. Notifiable communicable diseases include tuberculosis, various types of hepatitis, malaria, leprosy, measles, *Haemophilus influenzae* type b, syphilis, gonococcal infection, arbovirus infections (such as Ross River virus), chlamydial infection, meningococcal infection, mumps, pertussis, rubella, salmonellosis, and other diseases (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). Even though the reporting of various communicable diseases is required by law, the proportions of cases actually notified to health authorities are unknown and are likely to vary for different diseases and between jurisdictions (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). Of those cases notified, the proportions for which the question on Indigenous status is answered also vary widely. The only jurisdictions with levels of Indigenous identification sufficiently high in 1998-2000 to justify publication were WA, SA and the NT. For those jurisdictions, the proportions for which the question on Indigenous status was answered in 1998-2000 were 80% or better for all except two notifiable diseases (campylobacteriosis and pertussis), but the accuracy of identification is not known.[40]

In 1998-2000, the notification rates for people identified as Indigenous were higher than for the total population in WA, SA, and the NT for chlamydial infection, donovanosis, gonococcal infection, *Haemophilus influenzae* type b, hepatitis A, hepatitis B, hepatitis C, meningococcal infection, salmonellosis, shigellosis, syphilis and tuberculosis (TB), but lower or very similar for measles, pertussis, mumps, rubella, and Ross River virus (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

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Sexually transmissible infections

Background[41]

Sexual health issues within Aboriginal and Torres Strait Islander communities have been a matter of concern for a number of years, and have formed a key part of the Government's election commitments on Indigenous health (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). Among Indigenous Australians (and non-Indigenous Australians) there are culturally defined boundaries of social engagement that inform how and in what contexts sex can be talked about. Sexual health is a sensitive area in many Indigenous communities, and thus strategies need to be developed to accommodate these sensitivities. Maintaining client confidentiality is seen to be central in the

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[40] Data from the other jurisdictions was not reported, because the proportions for which the question on Indigenous status was not answered were very high - 'as high as 100% for some diseases in some jurisdictions' (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

[41] For more information about STIs and their impact among Indigenous people see the relevant sections of the Australian Indigenous Health*InfoNet* (www.healthinfonet.ecu.edu.au).

development of effective clinical and/or educational sexual health programs (Smith, Perry, Cutmore, & Combo, 1999).

Achievements

Sexual health and STIs are major public health issues among a number of Indigenous populations, but there have been some important successes in addressing this area (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). Successful programs take into account issues and key factors including: recognising the importance of community-based programs; encouraging community participation and interaction; dealing separately with women's and men's business; combining sexual education with clinical services; and incorporating sports days with strong community and sportsperson participation (Smith et al., 1999). Sexual health must be tackled as a specific problem, but the relatively high rate of STIs among Indigenous people is strongly linked to other health, employment, housing and education concerns. Thus, even when tackled in isolation from other concerns, sexual health programs still must be informed and well aware of the underlying problems associated with Indigenous health.

Nganampa Health Council, an independent, Aboriginal-controlled health service, has been fundamental in the implementation of STI control and HIV prevention programs in the Anangu Pitjantjatjara Lands (AP Lands) in the far north of SA (Nganampa Health Council, 1997). As a means of identifying successful strategies, ongoing evaluation of program activity is an important part of the program planning and implementation process. In 1998, Nganampa Health Council demonstrated that existing strategies of improving access to diagnosis and treatment were effective in reducing the prevalence of gonorrhoea (Knox, Miller, Hately, Mick, & Scales, 2000). Analysis of data from the 1999 STI screening demonstrates that the strategies have been successful also in reducing the prevalence of chlamydia (Knox et al., 2000). Prison education is another strategy used by Nganampa Health Council in addressing the issue of STIs on the AP Lands. Encouraging STI check ups before discharge from prison was addressed in the education sessions, and, as a result of these workshops, Nganampa Health Council was invited to visit the prison on a regular basis (Knox et al., 2000). The STI control and HIV program also maintains an ongoing role in regional STI orientation and training workshops, and provides regular in-servicing for Aboriginal health workers and non-Aboriginal clinic staff. These types of formal professional development programs are essential in developing the Indigenous workforce.

Ten years ago, 10% of the population in parts of central Australia had donovanosis (Miller, 2001). This disfiguring STI results in a form of ulceration, and can be a major factor in the transmission of HIV. In Australia, it is almost unknown outside of the Aboriginal and Torres Strait Islander population. The notification rate has been dramatically reduced as a result of the National Indigenous Australians Sexual Health Strategy. Through this strategy, there have been significant actions to strengthen the capacity of primary health care services, improvements in early diagnosis and treatment, better education strategies, and an extension of the partnership philosophy to encompass Aboriginal and Torres Strait Islander people. The success of the strategy to date in managing STIs has made available a unique opportunity to mount concentrated efforts to eradicate donovanosis. Significant headway has been made in the control of the infection in Australia in the last decade, and today donovanosis is in its final phase with a stubborn, but declining incidence in rural and remote Aboriginal communities (Miller, 2001).

As noted above, another successful program focused on the impact of improved diagnosis and treatment on the prevalence of gonorrhoea and chlamydial infection in communities on the AP Lands (Miller, Torzillo, & Hateley, 1999). An evaluation of the program demonstrated a rapid reduction in the prevalence of gonorrhoea, probably reflecting reduced duration of infectiousness due to advances in diagnosis, increased testing activity and reduced interval to treatment, rather than behaviour change. The success of this program was the result of improved accessibility of STI care, including the separation of men's and women's rooms, and male and female staff being available in all clinics. The promotion of early presentation for signs of STIs was important, as well as improved speed and accuracy in the diagnosis process. Improvements in the quality of case management and also the importance of reporting back to the community were fundamental to the program's success. It should be noted that communities on the AP Lands have had extensive experience in community STI screening and community-controlled programs, which have resulted in a decline in the incidence of syphilis. The importance of community control has been fundamental to the success of this program.

A review of HIV/sexual health projects in New South Wales concluded that no single approach was universally successful (Smith et al., 1999). Determining local need and encouraging as much interactive participation as possible were seen as important. Programs implemented throughout the State that were regarded as successful include: a men's sexual health conference; a rural sexual education program; a needs assessment; peer education training programs; combining sexual health education with clinical services; and involvement in schools. Evaluating the success or otherwise of a program was complicated. Some evaluation measures were quantifiable (such as attendance, level of community participation, and reductions in rates of STIs), and others qualitative (such as community ownership). A major problem in measuring the success or otherwise of sexual health programs is that they are frequently informal. Often, the informal approach is taken because it is the most appropriate pathway to a health intervention. This suggests that evaluations need to be flexible and supportive of innovative approaches, which may be more informal than traditional measures of success.

The compilation of Aboriginal sexual health workers' success stories from rural and remote settings throughout WA, has documented the ways in which Aboriginal sexual health workers work across the medical and cultural domains of sexual health (Coffin, 2001). There were many positive examples of how workers interacted collaboratively with both communities and other team members. The stories have the potential to enrich educational resources and materials, and assist in developing workers' skills and expertise in Aboriginal sexual health. Aboriginal health workers were seen as the best teachers for giving other health professionals insights into Aboriginal sexual health.

Summary

Improving the sexual health of Aboriginal and Torres Strait Islander people is not primarily a task of changing individual behaviours, and requires the provision of culturally appropriate and accessible primary health care (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). Ongoing evaluation of program activity is essential to identify successful strategies which need to be maintained, developed and implemented (Knox et al., 2000). It is evident from the literature that successful strategies have focused on improving access to diagnosis and treatment, client confidentiality, community control and participation, and have recognised the skills and knowledge of Aboriginal sexual health workers themselves. Finally, it can be concluded that, although sexual health needs to be addressed as a specific problem, the relatively high rates of sexually transmissible infections among Indigenous people is allied strongly to other health, housing, employment and education concerns (Smith et al., 1999). Sexual health programs, even when addressed in isolation from other concerns, need to be informed by an awareness and recognition of the underlying problems associated with Indigenous health.

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HIV/AIDS

Background

Epidemiology

Australia has so far successfully prevented an uncontrolled spread of human immunodeficiency virus (HIV) among its population, unlike many other nations. As a result, the numbers of cases of HIV and acquired immunodeficiency syndrome (AIDS) cases in Australia are among the lowest in the world. Likewise, the presence of HIV/AIDS in Indigenous people is generally low. However, current knowledge of HIV/AIDS and its associated risk factors suggests that the disease has the potential of becoming a serious problem for Indigenous Australians.

Current data on HIV/AIDS in Australia comes mainly from the national surveillance of HIV/AIDS by the National Centre in HIV Epidemiology and Clinical Research (NCHECR). In the seven-year period 1992-1998, there were 127 newly diagnosed cases of HIV in Aboriginal and Torres Strait Islander people. Overall, the incidence rate of 5.2 cases per 100,000 per year is very similar to the rate of 5.5 per 100,000 per year for the non-Indigenous population (Guthrie, Dore, McDonald, & Kaldor, 2000).[42] Yearly rates have generally been lower for the Indigenous population than the non-Indigenous population, but in 1998 the Indigenous rate of 7.2 per 100,000 was well above the non-Indigenous rate of 4.1 per 100,000.[43]

The general pattern of infection was similar generally for Indigenous and non-Indigenous people but there were some differences. For both populations, the majority of those infected were males, but the proportion of females infected was higher in the Indigenous population than the non-Indigenous population (National Centre in HIV Epidemiology and Clinical Research, 1999). Most HIV was transmitted through male homosexual contact, but there was a much greater proportion of heterosexual transmission in the Indigenous population than in the non-Indigenous population (37% compared with 14%). There appears to be a trend towards increasing numbers of heterosexually acquired cases for Indigenous and non-Indigenous populations (ANCARD Working Party on Indigenous Australians' Sexual Health, 1997). Transmission via injecting drug use was similar at 5% for Indigenous people and 3% for non-Indigenous people.

HIV policies and strategies

Many argue that the most effective HIV prevention strategies require the integration and coordination of clinical and population health (including health education), and that none of these

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[42] The overall figures conceal some important geographical differences, and outbreaks of HIV/AIDS have occurred in Indigenous communities.

[43] There were fewer cases notified among Indigenous people in 1999 (9 cases) and 2000 (12) than in 1998 (25) (National Centre in HIV Epidemiology and Clinical Research, 2001), so the incidence for 1998 appears to be a one-off peak due partly to the small numbers involved.

activities are likely to be effective if implemented in isolation (Anderson & Simmons, 1999). Significant cultural sensitivities in relation to the way in which the context of HIV can be discussed within communities have proved to be significant barriers to HIV prevention within Indigenous communities. However, the sensitivities associated with HIV and sexual health do not mean that informed community debate and discussion cannot be undertaken. Culturally acceptable dialogue and resources are fundamental in influencing community action, and also guiding program development. Significant developments in Aboriginal sexual health, more specifically HIV/AIDS, have been dependant on the role of the community, and its ability to bring community values and priories to the overall design of the program being implemented. Achievements have been made within the area of HIV/AIDS in the Indigenous community, but successful outcomes will be few and far between if better coordination and supportive services are not addressed for Indigenous people and the diversity of circumstances that they are presented with (ANCAHRD, 2000).

Achievements

There have been significant contributions from dedicated Indigenous people in response to the HIV/AIDS epidemic (ANCAHRD, 2000). These people have played a vital role in setting and maintaining the overall direction of policy and action in attempting to prevent and deal with HIV infection (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). There are no examples in the literature of specific outcomes in term of HIV prevention and/or management of HIV/AIDS, but there are clear examples of successful consultation and planning as well as the implementation of appropriate strategies.

For example, the Nganampa Health Council (NHC) and the Ngaanyatjarra Health Service (both Aboriginal community-controlled services) have undertaken extensive consultation, education and policy development exercises within the communities they serve. Both services found that the responses to HIV by communities were hostile initially, but, after increased consultation, education and policy development, attitudes moderated (Skov, Bowden, McCaul, Thompson, & Scrimgeour, 1996). Today, both services have community policies in place that protect confidentiality and care for HIV infected people within the community. Such consultation and planning does not necessarily guarantee an outstanding outcome, but it instils confidence in the community that the issue of HIV is being appropriately addressed (Skov et al., 1996).

The fear of breaches of confidentiality is a particular problem in dealing with HIV/AIDS generally, not just within the Indigenous population (ANCAHRD, 2000). This problem has been addressed successfully on the AP Lands in SA by the NHC, which introduced confidential coded testing for HIV testing in its clinics. Results indicated that the number of HIV tests increased dramatically after this strategy was initiated (Miller, Torzillo, & Hateley, 1998).

Resources which are culturally appropriate to Indigenous communities are fundamental in achieving improved access to appropriate health care information. Examples are the resource guide produced by the ANCAHRD, which is specifically aimed for Indigenous primary health care organisations (ANCAHRD, 2000), and the materials developed by the NHC as part of its HIV prevention programs. Materials include a pre-test information audio tape for women, an HIV education video for men, and a cartoon style HIV education video for young men who are not initiated (Nganampa Health Council, 1998). A wide range of locally developed and culturally relevant HIV/AIDS materials are now being used throughout Indigenous communities, and are successful in their objective of appropriately addressing their target groups.

A related issue is the employment of Indigenous staff in HIV/AIDS related programs. Employing the appropriate staff is a key factor in the way programs, particularly on sensitive subjects, are received by communities. The NHC's comprehensive STD Control and HIV Prevention Program, established in 1994, is an example of the employment of appropriate staff for certain positions. The work performed in this program is directed by separate women's and men's reference groups, and is under the formal direction of the Health Committee (Nganampa Health Council, 1998). Health worker education, which provides staff with appropriate accreditation for the training and courses they have completed, is also offered to all health workers on the AP Lands (Nganampa Health Council, 1998). Another example from the NHC is the 'Safe Ceremonies Strategy', which employs six senior Indigenous men on a retainer to oversee safe ceremonial practice. The aim of the project is to reduce the risk of transmission of blood borne viruses, including HIV. No formal evaluation has been published, but the strategy has been considered successful and has been extended, with the cooperation of Territory Health Services, to southern communities in the NT and the Ngaanyatjarra communities in WA.

The need for culturally appropriate resources and the employment of appropriate Indigenous workers is important, and so is the need for non-Indigenous staff to work successfully with Indigenous staff and communities. The support by the ANCAHRD for the education of isolated health professionals in the area of HIV/AIDS (and hepatitis C and related diseases) is of great importance (ANCAHRD, 2002). The program is based on the fact that health service providers need education, support and appropriate resources to be able to provide appropriate care (Scott, 1997). Building local capacities and strengthening health partnerships is vital to this.

The establishment of partnerships and networks in the area of HIV/AIDS is an important area. The approach to the HIV epidemic in Australia has generally been characterised by a partnership between government, medical professionals and the affected community (Scott, 1997) (Queensland Health, 1999). The partnership approach has been fundamental to Australia's HIV policy since the beginning of organised action to combat the virus. The extension of this partnership philosophy has been brought to the National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99, incorporating the need to encompass Aboriginal and Torres Strait Islander people and organisations (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). This particular strategy emphasises community involvement at every level of the decision making and policy formation processes, recognising that a lack of partnerships has in the past, been a major contributing factor to the lack of success of programs (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997).

Another example of the development of effective partnerships can be viewed in the collaborative effort between the South Australian Correctional Services Department and NHC staff in the provision of health education messages for inmates in the Port Augusta Prison (Nganampa Health Council, 1998). NHC provides other examples of effective partnerships in regard to collaborative efforts in the area of HIV/AIDS. As noted above, extension of the Safe Ceremonies Strategy was made possible through partnerships and cooperation between Territory Health Services and the Ngaanyatjarra communities of WA (Nganampa Health Council, 1998).

Summary

Many people in Indigenous communities still fear and misunderstand HIV/AIDS (ANCAHRD, 2000), but substantial progress has been made in recent years. Achievements in the area of HIV/AIDS in Indigenous communities can be seen in the areas of consultation, education and policy development. Key strategies include development of culturally appropriate resources, the employment and training of appropriate Indigenous and non-Indigenous staff, the integration and coordination of clinical and population health and health education activities, and the development of effective partnerships.

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Hepatitis

Background

Hepatitis is an inflammation of the liver and has numerous causes, including viral infection, alcohol or drug abuse, and the body's immune system attacking itself (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997). It can be a short-term, acute illness or a persistent, chronic disease. A number of viruses are responsible for viral hepatitis, with types A, B, and C being the most common (types D through G have been identified also). Each virus causes a different manifestation of disease and each is transmitted in different ways (Commonwealth Department of Health and Family Services. Office for Aboriginal and Torres Strait Islander Health Services, 1997).

Hepatitis A

Hepatitis A (HAV) is caused by an enterovirus and is transmitted principally through food and water contaminated with faecal matter from an infected individual (The Australasian College of Sexual Health Physicians, 1999). HAV infection is preventable by vaccine, which is highly recommended for at-risk individuals, including those who travel and are exposed to water of questionable quality. Thorough hand-washing with soap and warm water is the most effective preventive measure. Improved sanitation and personal hygiene have reduced its incidence in most urban areas of Australia, but foci of infection persist and, in special circumstances, HAV vaccination is likely to be beneficial (Bowden, Currie, Miller, Locarnini, & Krause, 1994).

In 1998-2000, one-fifth of the 1,071 notifications of hepatitis A in WA, SA and the NT combined were identified as being Indigenous (in 12% of notifications, Indigenous status was not stated) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). The crude notification rate of 52.9 per 100,000 for Indigenous people was more than 5 times the rate of 10.1 per 100,000 for non-Indigenous people. The real incidence of hepatitis A is likely to be much higher among Indigenous people than these figures suggest, however, as the disease is endemic among many rural and remote communities (Australian Indigenous Health*InfoNet*, 2001; Bowden et al., 1994; Merritt, Symons, & Griffiths, 1999).

Hepatitis B

Hepatitis B (HBV) is transmitted by similar means to HIV, but with 10 to 40 times greater efficiency (The Australasian College of Sexual Health Physicians, 1999). Transmission primarily occurs due to contact with the blood and other body fluids (semen, vaginal fluids, and saliva) of an infected individual, commonly through sexual contact or use of contaminated injecting equipment. A mother may also transmit HBV to the foetus during pregnancy (ANCARD Working Party on Indigenous Australians' Sexual Health, 1997).

At least two to four per cent infected with HBV develop a chronic disease and can continue to infect others (The Australasian College of Sexual Health Physicians, 1999). People with chronic hepatitis B (and hepatitis C) infections risk long-term liver damage and complications (such as cirrhosis and primary liver cancer) (The Australasian College of Sexual Health Physicians, 1999).

In 1998-2000, 23% of the 296 notifications of acute hepatitis B in WA, SA and the NT combined were identified as being Indigenous (in 6% of notifications, Indigenous status was not stated) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). The crude notification rate of 16.7 per 100,000 for Indigenous people was more than 5 times the rate of 2.8 per 100,000 for non-Indigenous people.

In terms of chronic hepatitis B, historical and more recent studies have consistently shown a higher prevalence of HBsAg (a serological marker for HBV) in the Indigenous community than in the general population (Australian Indigenous Health*InfoNet*, 2001). Overall, Australia has a low prevalence of hepatitis B, but some Indigenous populations have levels comparable with countries with the highest prevalence of HBV infection. A number of studies have reported finding HBsAg in around one-quarter of Indigenous people surveyed in central Australia and neighbouring parts of WA and SA (Australian Indigenous HealthInfoNet, 2001).

In view of the high prevalence of hepatitis B markers in many Indigenous populations, vaccination against the disease was offered to Indigenous newborn infants from around the mid 1980s. Queensland began their program in late 1985, and supplemented it in 1987 with a catch-up program for Indigenous children up to 10 years of age (Malcolm, Ludwick, Brookes, & Hanna, 2000). The Queensland initiative prompted the Commonwealth Government to provide funds from 1988 for the vaccination of all Indigenous infants (National Health and Medical Research Council, 2000). At around the same time, health authorities in WA launched a vaccination program targeting all Indigenous people up to 19 years of age (Gill, Bucens, Hatton, Carey, & Quadros, 1990). Since May 2000, the vaccination of all babies has been recommended (Commonwealth Department of Health and Ageing, 2001).

Hepatitis C

Infection with hepatitis C virus (HCV) can occur via contact with contaminated blood (typically through sharing of needles during IV drug use or tattooing) or through blood transfusions (National Centre in HIV Epidemiology and Clinical Research, 2000). Improved testing of blood to be used in transfusions has reduced the risk of infection by this route to 1 in 100,000. HCV can also be passed from mother to foetus during pregnancy. Though conflicting reports exist, sexual contact may be another potential route of transmission and safe sexual measures should always be taken (National Centre in HIV Epidemiology and Clinical Research, 2000). As is the case with hepatitis B, HCV infection can be chronic, leading potentially to cirrhosis and or primary liver cancer (National Centre in HIV Epidemiology and Clinical Research, 2000).

No vaccine exists for HCV. Preventive measures include avoiding IV drug use. Injecting drug users should always use a sterile needle and never share needles. Razors, toothbrushes, and any other items that may have contacted blood or bodily fluids should not be shared (National Centre in HIV Epidemiology and Clinical Research, 2000). Currently, there is no treatment for HCV.

In 1998-2000, 13% of the 630 notifications of acute hepatitis C in WA, SA and the NT combined were identified as being Indigenous (in 4% of notifications, Indigenous status was not stated) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001). The crude notification rate of 19.2 per 100,000 for Indigenous people was more than 3 times the rate of 5.9 per 100,000 for non-Indigenous people.

Achievements

Hepatitis A

There were no examples in the literature of specific outcomes in term of hepatitis A prevention and/or management, but two reports demonstrate progress in the understanding of appropriate medical strategies for the disease among Indigenous people.

Based on a study of the epidemiology and effectiveness of vaccination programs, with particular attention to 'herd immunity', it was concluded that vaccination in some communities may not necessarily be the most effective way of appropriately dealing with hepatitis outbreaks (Bowden et al., 1994). Vaccination still remains the best action for non-immune individuals, but it is not appropriate for Indigenous children who may have developed an acquired form of immunity. It was suggested that education of remote communities as well as change in health infrastructure may be the best solution to hepatitis A transmission in those communities (Bowden et al., 1994).

A study of the deaths of three Indigenous children in north Queensland from fulminant hepatitis A concluded that, even if the children had been able to undergo liver transplantation and/or prolonged immunosuppressant therapy, the likelihood of opportunistic infections would inevitably have jeopardised any chance of long-term survival (Hanna, Warnock, Shepherd, & Selvey, 2000). The vaccination of pre-school Indigenous children was seen as important in preventing further cases of fulminant hepatitis A and in the reduction of future outbreaks in Indigenous communities. An earlier study of the epidemiology of acute hepatitis A in north Queensland was more cautious, suggesting that appropriate sero-prevalence studies were needed before commencing an immunisation program in Indigenous communities (Merritt et al., 1999). Subsequent documentation of a mean age of 12.6 years for cases of hepatitis A among Indigenous people resulted in hepatitis A vaccination being offered to Indigenous children in north Queensland since early 1999 (National Health and Medical Research Council, 2000).

Hepatitis B

As noted above, vaccination programs against hepatitis B commenced in Australia for Indigenous infants and children from around the mid 1980s. Generally, however, the vaccination programs have been less effective than anticipated (Gardner, Wan, & Mathews, 1990; Hanna, Faoagali, Buda, & Sheridan, 1997; Hanna et al., 1995; Wan, 1994). Possible reasons for the relatively high frequency of non-response in Indigenous infants and lower levels of antibody in those who did respond include problems in maintaining vaccine immunogenicity in remote areas, the comparatively poor health and nutritional status of Indigenous infants, and genetic factors (involving class II HLA antigens) (Gardner et al., 1990). An evaluation of the routine HBV vaccination program in the NT from February 1992 to March 1993 found that only 61% of Indigenous children had satisfactory hepatitis B surface antibody levels four years after their first dose of vaccine (Wan, Guthridge, Green, Currie, & Mathews, 1995). The success of the administration of a fourth vaccine dose to those Indigenous children whose antibody level had been assessed as unsatisfactory suggested that some variation of the routine vaccination schedule was necessary to ensure adequate immunity.

Despite the less than optimal responses to the HBV vaccination programs for Indigenous infants, there has been a marked reduction in the prevalence of markers of HBV infection and carriage since introduction of the programs (Hanna et al., 1997).

Hepatitis C

In view of the fact that there is neither a cure nor a vaccine for HCV, achievements can relate only to a better understanding of the disease and its risk factors, and to programs addressing these risk factors (Butler et al., 1997). The only literature in this regard relates to the former aspect, as it is now clear that HCV has become a significant health problem for many Indigenous people.

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Gastrointestinal disorders

Background

Gastrointestinal disease is a significant problem among Indigenous people, particularly infants and young children. The conditions affecting children are predominantly intestinal infections, causing diarrhoea, and parasitic infestations. This section will consider only childhood gastrointestinal disorders, particularly diarrhoea.

Diarrhoea is not a major problem among non-Indigenous children, but it remains a common cause of morbidity and hospitalisation and occasional mortality among some Indigenous children. The incidence of diarrhoea in some remote Aboriginal communities has been documented as one of the highest in the world (Skov, 1994). Hospital admission rates for Western Australian Aboriginal infants with diarrhoea were 9 to 11 times more frequent than for non-Aboriginal infants during the period 1980-1991 (Gracey & Gee, 1994). Once in hospital, most Aboriginal children with diarrhoea had to stay about twice as long as other children due to the severity of their condition. The mortality from diarrhoea alone in Aboriginal children is greater than the mortality in non-Aboriginal children from all types of infections combined (Silva, Ruben, Wronski, Stronach, & Woods, 1998).

Diarrhoea is usually caused by the transmission of pathogenic microorganisms from faeces to the gastrointestinal tract via the mouth. Thus, contaminated water and food are the major sources of diarrhoeal infection. Such contamination is facilitated by overcrowding and unhygienic living conditions prevailing in many Aboriginal communities. Other factors influencing diarrhoeal infections are the nature of the infecting organism, host factors (such as immune status and nutrition) and external factors (including climate, season and the presence of human and animal vectors) (Gracey, 1993a).

As well as acute diarrhoea, many Indigenous children experience more health problems from other gastrointestinal infections and infestations than do most non-Indigenous children (Gracey, 1998). Of the various infections and infestations, three warrant special mention: *Giardia lamblia;* hookworm and strongyloides.

Giardia lamblia, the most commonly reported intestinal parasite in Australia, was found in stool specimens of 32% of Indigenous children and 12.5% of Indigenous adults surveyed in the Kimberley region of WA during 1988-1991 (Meloni, Thompson, Hopkins, Reynoldson, & Gracey, 1993). Detailed data are not available for other regions, but giardiasis is likely to be a problem in many rural and remote areas of Australia. Giardiasis can cause acute diarrhoea and malabsorption, and also persistent diarrhoea in children, and can thus contribute to growth retardation (Gracey, 1993b).

Of the various helminths infesting Indigenous people, hookworm and strongyloides are of greatest public health significance. Hookworm causes considerable morbidity in the form of anaemia, and strongyloidosis, although less prevalent than hookworm disease, is potentially more pathogenic and is fatal occasionally (Prociv, 1990).

Intensive and repeated use of antihelminthic drugs and improved living standards have virtually eliminated the disease in north Queensland (Prociv & Luke, 1993), but it remains a problem in other parts of northern Australia. A recent survey in an Aboriginal community in the Kimberley region of WA found an overall prevalence of 77%, with the highest prevalence (93%) being in children aged 5-14 years (Hopkins et al., 1997). Hookworm infestation is known also to be a problem in the NT, but actual figures are not available.

Strongyloides is well established in most Aboriginal communities in northern Australia. In north Queensland, the annual prevalence of the parasite has varied depending on the year and community surveyed. Over a the 20 year period 1972-1991, the highest average annual prevalence recorded was 12% in Doomadgee (Prociv & Luke, 1993). For the 52 Aboriginal communities in Queensland that provided records during that period the average annual prevalence was almost 2%. There is a seasonal variation with the highest prevalence being during the wet season. Given the wide seasonal variation and the ability of a single-specimen examination to identify only 74% of the cases, the documented prevalence is probably an underestimate (Prociv & Luke, 1993).

In the Top End of the NT, strongyloides is also endemic in Aboriginal communities. There have been no systematic surveys, but a review of the clinical records at the Royal Darwin Hospital during 1991-1992 showed that strongyloides was the second most common parasite seen at the hospital (Fisher, McCarry, & Currie, 1993). Of the 68 patients with strongyloidiasis, 64 were Aboriginal.

The risk of strongyloides infection is limited mainly to the tropical north in WA, and the prevalence appears quite low. A survey conducted in the Kimberley region during 1988-1991 found that the prevalence was only 0.3% in children aged 0-13 years, with no one affected above this age (Meloni et al., 1993).

Achievements

In view of the potential problems of diarrhoeal disease and gastrointestinal infestations for many Indigenous children, particularly in the north of Australia, it is somewhat surprising that the literature on the subject is so sparse. Of the literature that could be identified, attention is directed almost entirely to the descriptive epidemiology and clinical features of the various diseases.

Of course, since many gastrointestinal disorders are related to contaminated environments (including overcrowding and unhygienic living conditions) and host factors (such as immune status and nutrition), achievements in these areas are likely to result also in reductions in the frequency and severity of diarrhoea and other diseases.

Anecdotal reports suggest that this has, in fact, happened with regard to diarrhoeal disease. These anecdotal reports are supported by hospital admission figures. The analysis of hospitalisation rates for Western Australian Aboriginal infants with diarrhoea found considerable improvements over the period 1980-1991 (Gracey & Gee, 1994).

As noted in the section on nutrition, a nutritional intervention resulted in a 70% decline in hospital admissions due to gastrointestinal and nutritional problems for children under the age of five years living in a central Australian community (Warchivker, 2000).

It is likely that there are many other achievements in the area, but they were either not located by this review or have not been written up – even in the grey literature.

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Haemophilus influenzae type b

Background

H. influenzae type b (Hib) is a gram-negative bacterium found among the normal flora of the human respiratory tract (Clements & Gilbert, 1990b). Colonisation with Hib does not necessarily result in infection and disease, but the bacterium can give rise to considerable morbidity and mortality (Gilbert, 1992b; McIntyre, 1992). In the past, Hib has been responsible for a large proportion of the most serious forms of *H. influenzae* disease, the clinical manifestations of which include meningitis, epiglottitis, pneumonia, septicaemia, cellulitis, osteomyelitis, pericarditis and septic arthritis (Bower, 1993; Gilbert, 1992a). Hib is spread by respiratory secretions, and the majority of cases occur between the ages of a few months and five years of age (Bijlmer, 1991; Clements & Gilbert, 1990a; Clements & Gilbert, 1990b).

Hib infections are now preventable and the introduction of vaccination programs in more than 20 other countries around the world (including Australia) has seen the near eradication of Hib disease from many developed countries (Steinhoff, 1997).

Hib in the pre-vaccination era

As recently as a decade ago, prior to the introduction of Australia's national vaccination program, the various forms of invasive Hib disease represented a significant threat to the health and wellbeing of all Australian children. At that time, it was estimated that between 500 and 700 Australian children contracted invasive Hib disease annually (Harris et al., 1994; Herceg, 1995; Moor, Collignon, & Gilbert, 1999). Meningitis[44], one of the most serious forms of invasive Hib disease, can cause significant morbidity and is potentially fatal (McIntyre, 1992; McIntyre, Jepson, Leeder, & Irwig, 1993).

Of the children contracting invasive Hib disease around 20 died (Harris et al., 1994; Isaacs, 1994; McIntyre, 1992), approximately 20 suffered severe, permanent neurological handicap, and many more were left with other, less profound neurological impairment (Harris et al., 1994; Isaacs, 1994). The impact of Hib varied between childhood populations and, in the late 1980s and early 1990s, a series of studies highlighted marked differences between Indigenous and non-Indigenous children in the epidemiology of Hib disease (Bower, 1993).

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[44] Meningitis, which is inflammation of the tissues that cover the brain and spinal cord, can be caused by bacteria and viruses. Apart from *Haemophilus influenzae* type B, other bacteria that can cause meningitis include *N. meningitidis*, *Streptococcus pneumoniae* (pneumococcus) and group B streptococcus. Treatment requires intensive care, and antibiotic therapy for bacterial infections.

In the era preceding vaccination, Indigenous children, particularly those from rural areas, exhibited patterns of Hib infection similar to those documented in developing countries and among the most disadvantaged populations in developed countries (Clements & Gilbert, 1990a; Gilbert, 1991). Meningitis and pneumonia were the most common manifestations (Gilbert, 1991; Hanna & Torzillo, 1991; Moor et al., 1999). Incidence estimates for Indigenous children from this period varied across geographic locations, but were consistently greater than those reported for non-Indigenous children (Gilbert, 1991; Hanna, 1992). In central Australia, incidence rates were higher than those reported anywhere else in the world (Hanna, 1990). Disease was typically contracted before the age of one year (Gilbert, 1991; Hanna, 1992), and there was a greater risk of mortality and long-term morbidity (Bower et al., 1994; Hanna, 1990).

It has been suggested that the burden of Hib disease observed in the Indigenous population prior to vaccination may have been due in part to their exposure to more virulent strains of Hib (Moor et al., 1999), or to genetic differences in susceptibility (Hanna, 1992). However, high incidence rates were largely influenced by inadequate social and environmental conditions including: poor nutrition; low levels of breastfeeding among urban Indigenous populations; poor living conditions and overcrowding; and other environmental conditions (such as exposure to woodsmoke, dust, and passive smoking) (Hanna, 1992).

In the years immediately preceding the introduction of Hib vaccination, incidence rates for Hib disease among Indigenous children varied between States and Territories. Estimates ranged from a complete absence of the disease among Indigenous people in the ACT (McGregor, Bell, Abdool, & Collingnon, 1992) to 115 cases per 100,000 population in Queensland (Scott, 1993), 225 per 100,000 in WA (Bower et al., 1998), 530 per 100,000 in the NT overall, and 990 per 100,000 in central Australia (Hanna, 1990). The latter rate is higher than any reported internationally (Moor et al., 1999), and of an order of magnitude above and beyond that reported elsewhere in the nation (McGregor et al., 1992).

The medical and social importance of Hib infection generally, and within Indigenous populations particularly, resulted in the implementation in July 1993 of a fully-funded national infant program. Funding for a national 'catch-up' program targeting all children up to 5 years of age commenced in August 1993 (Bower et al., 1998; Isaacs, 1994).

Achievements

A number of studies conducted in the period following the introduction of Hib vaccines documented a marked decrease in the incidence of invasive Hib disease in Australian children (Bower et al., 1998; Hanna & Messer, 1995; Herceg, 1995; Markey, 1998). Both the Hib Case Reporting Scheme and the National Notifiable Diseases Surveillance System documented a fall of approximately 50% in the number of cases of invasive Hib disease reported in Australia between 1 July 1993 and 30 June1994 (Herceg, 1995).

In WA, figures for 1994 demonstrated a rapid decline in the incidence of invasive Hib disease in both Indigenous and non-Indigenous children following the introduction of vaccination (Bower et al., 1998). However, three cases of invasive Hib infection were reported in fully vaccinated Indigenous children and the study was unable to demonstrate that Hib vaccination conferred a statistically significant benefit for the Indigenous population. In contrast, not a single case of Hib meningitis was reported in Indigenous people in far north Queensland between July 1993 and the end of 1994 (Hanna & Messer, 1995). In the NT, the incidence of invasive Hib disease in Indigenous children dropped from 278 cases per 100,000 children-years in the pre-vaccination period (January 1989 to June 1993), to 37 per 100,000 in the post-vaccination period (July 1993-December 1996) (Markey, 1998). The relative risk of disease in Indigenous children following the introduction of vaccination, compared with the risk before vaccination, was calculated to be 0.13. Today in the NT, Hib disease is considered rare (Markey et al., 2001).

A recent analysis of the effectiveness of the NT Hib conjugate vaccine program (Markey et al., 2001) found that incidence rates fell to a seventh of their pre-vaccination level, in both

Indigenous and non-Indigenous children, following the introduction of the vaccine. The PRP-OMPC vaccine was calculated to be 97.5 effective and the overall effectiveness of the vaccination program was calculated at 86.3%.

Summary

The success of the Hib vaccination program is a notable achievement. However, despite the rapid decrease in the number of reported Hib cases, nasopharyngeal carriage of Hib persists (Leach, Shelby-James, Morris, & Mathews, 1997) cited in (Smith-Vaughan, Sriprakash, Leach, Mathews, & Kemp, 1998), and invasive disease continues to occur. Between July 1993 and June 1996, Australia-wide surveillance identified 412 cases of invasive disease due to Hib. Included were 18 deaths and 34 cases of vaccine failure (according to the Australian case definition of a vaccine failure) (Herceg, 1997). Two of the deaths were of Indigenous children, as were four of the vaccine failures. Between 1997 and 2000, five cases of Hib disease were reported in the NT. All occurred among Indigenous children (3 immunised, 2 unimmunised) (Markey et al., 2001). Ongoing surveillance is therefore necessary to evaluate the continuing efficacy of the Hib vaccination program and associated disease control activities.

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Meningococcal disease

Introduction

Meningococcal disease, caused by *Neisseria meningitidis* (meningococcus), is now the most common cause of bacterial meningitis in Australia. It is also an important cause of overwhelming sepsis in otherwise healthy young people, with a case fatality rate of around 10% (National Health and Medical Research Council, 1997). Asymptomatic respiratory tract carriage of the organism is present in up to 20% of the population, and the prevalence may be higher when groups of people occupy small areas of living space. Infection tends to occur in small localised clusters, often within the members of a household, a pre-school groups or a military unit, probably because of the spread within the group of a virulent strain of the organism (National Health and Medical Research Council, 1997). The disease is vaccine preventable. Close contacts who have become colonised with a virulent strain may develop invasive meningococcal disease – the risk is greatest in the first week after contact but may persist for many months. Survivors of meningitis commonly have neurological sequelae, such as deafness and intellectual impairment. Epiglottitis is another major category of infection, and less common manifestations include cellulitis, septic arthritis, pneumonia, pericarditis, osteomyelitis, and septicaemia (National Centre for Immunisation Research and Surveillance, 2000).

Meningococcal disease occurs worldwide in both epidemic and endemic forms. In Australia, as in western industrialised countries, the infection is largely sporadic, occurs mostly in winter and spring months, and is mostly caused by serogroup B and, to a lesser extent, serogroup C (Communicable Diseases Network Australia, 2001; National Health and Medical Research Council, 2000; Patel, 1997). This pattern differs greatly from that seen historically in Australia (and other industrialised countries), when serogroup A was the predominant form of the disease (Patel, 1997). Serogroup A meningococci remain the cause of major epidemics in developing countries (particularly in the 'meningitis belt' of sub-Saharan Africa), and were the cause of outbreaks in Indigenous populations in central Australia in 1987-1991 (Patel et al., 1993). In contrast, there were no cases caused by serogroup A meningococci in a number of small outbreaks of invasive disease in Indigenous communities in north Queensland in 1990-1994, where serogroup C was the most common strain (Hanna, McCall, & Murphy, 1996).

Overall, meningococcal infection is much more common among Indigenous than non-Indigenous people – in 1988-2000, the crude notification rate for Indigenous people living in WA, SA and the NT was 14.8 per 100,000, almost five times the rate of 3.0 for the total population in those jurisdictions (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2001).

Achievements

The responses to the outbreaks of invasive meningococcal disease in central Australia and north Queensland appear to have been successful in restricting the further spread of the disease (Hanna & Alexander, 1994; Pearce et al., 1995). In each case, the response involved the use of a prophylactic antibiotic (usually rifampicin, but ceftriaxone has also been used) and vaccination for people living in the communities involved.

In addition to this direct impact, the outbreaks resulted in more attention being directed to the disease among Indigenous people. This has led to the development of specific guidelines for handling outbreaks in Indigenous communities (Communicable Diseases Network Australia, 2001; National Health and Medical Research Council, 1997; National Health and Medical Research Council, 2000). Also, some jurisdictions have adopted enhanced surveillance for meningococcal disease (Ward, Hanna, Bates, & Selvey, 2000), which should benefit Indigenous and non-Indigenous people.

Of course, real success in addressing invasive meningococcal disease among Indigenous people would result in decreased incidence and mortality from the disease. There is evidence of a reduction in the incidence of invasive meningococcal disease in Indigenous communities in north Queensland since the early 1990s, even though the incidence for Indigenous people was still three times that of non-Indigenous people in 1995-1999 (Harley, Hanna, Hills, Bates, & Smith, 2002). The reasons for the reduced incidence are not clear, but the three-fold difference between Indigenous and non-Indigenous people in incidence rates and the almost five-fold difference in the notification rates for WA, SA and the NT (see above), emphasises the persisting disadvantages experienced by Indigenous people.

Due to the sporadic nature of the disease, it is likely that elimination of the differences between Indigenous and non-Indigenous people in the incidence of invasive meningococcal disease will, along with a number of other diseases, depend more on improvements in the social and environmental conditions of Indigenous people than on health sector responses. In the meantime, however, the recent clinical and public health initiatives should contribute to some reductions in the incidence and impact of invasive meningococcal disease.

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Skin infections and infestations

Background

Skin infections that most commonly affect Aboriginal communities in Australia are scabies, pyoderma, fungal skin infections and a range of other skin infections caused by bacteria (Currie & Carapetis, 2000).[45]

Scabies is endemic in many remote Aboriginal communities, particularly in central and northern Australia, with prevalence of up to 50% in children and up to 25% in adults (Currie & Carapetis, 2000). The high levels of scabies infestation contribute to pyoderma, with up to 70% of Aboriginal children in some communities having skin sores. The major pathogen is group A streptococcus (GAS), which is responsible for continuing outbreaks of post-streptococcal glomerulonephritis and acute rheumatic fever (ARF).

The anthropophilic dermatophyte, *Trichophyton rubrum*, is ubiquitous in many communities, again reflecting living conditions (Currie & Carapetis, 2000). Other skin infections which relate to the tropical environment include melioidosis, nocardiosis, *Chromobacterium violaceum* and chromoblastomycosis.

Sustainable and long term improvements in relation to skin diseases require fundamental changes that address social and economic inequities, and in particular, living conditions and overcrowding (Currie & Carapetis, 2000). Reductions in rates of skin diseases, and the development of treatment protocols, including standards of care, have been demonstrated in some Indigenous communities, but there is still a long way to go.

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[45] Recent information about skin infections and infestations comes almost entirely from northern Australia, particularly the Northern Territory.

Achievements

A successful community program to control scabies has occurred in a Top End community over the last few years. With community support and education there was a single community scabies treatment for all residents at the same time, and continued maintenance of the program, including screening, ongoing community education and evaluation of the program (Carapetis, Connors, Yarmirr, Krause, & Currie, 1997). This program, which was adapted from a successful model implemented in Panama (Taplin, Porcelain, & Meinking, 1991), involved the treatment of the whole community, using 5% permethrin cream. In all of the participating NT communities there has been a decrease in the number of people suffering from scabies (Carapetis et al., 1997).

The factors making programs effective and sustainable have been identified as: extensive community education and collaboration with community organisations; one-off community scabies treatment; on-going surveillance and follow-ups; focus on 'washing kids'; and identification and treatment of crusted scabies (Connors, 2001). A study of scabies in one Indigenous community found that the prevalence of scabies, infected scabies, and non-scabies pyoderma were 35%, 12% and 11% before the intervention, and 3%, 1% and 4% six-weeks after the intervention (Wong et al., 2001). Low prevalences were maintained at four and seven-month follow-up. This intervention, which revolved around community motivation, involvement and control, successfully reduced the prevalence of scabies. Empowerment and involvement of the whole community facilitated a successful outcome, because it was implemented within the community setting.

The Galiwinku Indigenous community near Echo Island, east of Darwin, has developed a video and brochure to educate residents on preventing scabies. One of the resources was a 'scabies flipchart'. This educational tool describes what scabies are, the different types of scabies, how you get scabies, how you treat them, and why we need to research scabies (Cooperative Research Centre for Aboriginal and Tropical Health, 2001). As the Top End of Australia has a diverse range of spoken languages, the flipchart was designed to be more pictorial than literal. This particular resource has been developed so that it is suitable for health practitioners, remote community clinics and schools (Cooperative Research Centre for Aboriginal and Tropical Health, 2001).

In regard to educational resources, a handbook of skin conditions in Indigenous populations of Australia has been produced recently (Green, 2001). The handbook provides a useful and easy way for people working in Indigenous health to identify and distinguish skin conditions endemic in some communities. It is aimed at assisting those concerned in making more informed clinical decisions. This resource also addresses issues of advocating for government policy that will address the environmental and socioeconomic determinants of health in a field where there is a continued need to address serious health inequalities.

Summary

Skin infections and infestations in Indigenous communities reflect serious health inequalities (Currie & Carapetis, 2000). The solutions to diseases of poverty are to be discovered in improved community infrastructure and Indigenous control over matters of health (Green, 2001). Despite inherent setbacks in this area, guidelines have been developed for community control of scabies and skin sores, and successful community-initiated coordinated programs have occurred (Currie & Carapetis, 2000). For ongoing and long-term improvements in regard to skin related diseases, fundamental changes that address social and economic inequalities, in particular, living conditions and overcrowding, are required.

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6.5 Other conditions

Injury

Background

Injury affects every Australian sometime in their lives and is a major health problem in Australia, accounting for 6% of all deaths, 47% of deaths in the 0 to 44 years age group, and 70% of deaths in young males (National Injury Prevention Advisory Council, 1999). It is responsible for 400,000 hospital admissions and estimated direct medical costs of $2,600 million a year. Accordingly, injury prevention and control is a National Health Priority Area (NHPA) – with the main goal of reducing costs to the health care system.

Broadly speaking, injury is physical harm or damage to the body (Ashwell, Pinder, & Thomson, 1996). It may be intentional or unintentional. If intentional, the injury may be self-inflicted (for example, suicide) or inflicted by another (for example, assault, homicide, etc.). The harm can be as a result of an external force (for example, collision with a moving object or a moving person colliding with a stationary object) or energy (such as heat and electricity); external or internal contact with a harmful substance (for example, poisoning); or absence of essential elements (such as oxygen and heat). Normally, only harmful effects occurring over a short period of time are classified as injuries. For example, the harmful effects of smoking or alcohol are not classified as injury, but overuse injuries (such as sport or work-related injuries) are.

For the purposes of this review, particular attention is directed to transportation injury and intentional injuries (self inflicted or inflicted by others). Suicide has been incorporated within the *Mental health including social and emotional wellbeing* section of the literature review, though it could be placed under either section depending upon the perspective taken.

The available data leaves a lot to be desired, but they are adequate enough to show that the burden of injury is much higher for Indigenous people than it is for the Australian population as a whole (Cunningham & Paradies, 2000). Injury is the second most common cause of death for Indigenous Australians, and death from injury is 3 to 3.5 times more common for Indigenous than for non-Indigenous people. Injury is the most common cause of hospitalisation among Indigenous males and the third most frequent cause among Indigenous females (excluding renal dialysis for both males and females).

Much remains unknown about injury among Indigenous people, but enough is known to reveal that injury intersects with other health and social issues. The proportion of Indigenous people living in rural and remote areas (with the risks associated in these environments) and differences in activities associated with cultural norms intersect closely with Indigenous injury.

Alcohol related injury is a major focus of injury prevention in Indigenous communities, as it is a very common precipitating factor (Harrison, Miller, Weeramanthri, Wakerman, & Barnes, 2001). The effects of alcohol on Indigenous injury are so damaging that it is often seen as the only cause of the problem.

Until a decade ago, little attention was directed to the prevention of any form of injury among Indigenous people, despite the fact that injuries contribute disproportionately to many of the health disadvantages they experience (Reid & Trompf, 1991). The recent literature shows that increasing attention is being given to the design and implementation of injury prevention projects/programs. Impetus for this relatively recent increase in action may be in part due to the situation among Indigenous people in New Zealand, Canada and the United States, where the success achieved generates considerable confidence that effective action in Australia is capable of producing substantial changes in Indigenous health.

Strategies for injury prevention

Most injuries follow predictable patterns of occurrence and are thus largely preventable. Unfortunately, in most areas of injury prevention the greatest barrier to implementing intervention strategies lies with lack of knowledge about effective interventions (National Injury Prevention Advisory Council, 1999). This lack of knowledge is due, at least partly, to the fact that the full extent of the differentials in injury between Indigenous and non-Indigenous people have only recently been recognised. In addition, the heterogeneity of lifestyles, lack of resources for interventions and their evaluation, and limited methods of evaluating interventions targeting small communities have limited the scope, quality and relevance of evidence.

There is a strong need for well-researched, action-oriented intervention development and evaluation research in partnership with Indigenous people as identified by the National Injury Prevention Advisory Council (National Injury Prevention Advisory Council, 1999).

Injury prevention strategies can be considered in three categories:

- ***Education/economic*** **–** campaigns aimed at providing people with information and/or rewards that will encourage changes in behaviour and help to prevent injuries;
- ***Environmental/engineering*** – for example, putting seat belts and shatterproof windscreens into all cars, roll-proof cages on the backs of utilities, smoke detectors into houses, and child-resistant closures on medicine bottles have been shown to be very effective in reducing both the number and severity of injuries, as has limiting access to alcohol ;
- ***Legislation and enforcement*** – for example, laws that limit the availability of guns, set safety standards for goods, and require motorcyclists to wear helmets have had important effects in some countries.

Assessing achievements

Information on evaluating the performance of injury prevention programs/interventions is extremely patchy:

> This is particularly the case for assessments of efficacy. Where jurisdiction-wide programs have been instituted or where numerous interventions have targeted the same topic, there does appear to be a growing body of information. Community-level interventions are quite numerous, especially in the topic areas of alcohol and, more recently, violence…most programs remain largely undocumented, and documented evaluations are rare. Formal documentation of community-level interventions aimed at issues other than alcohol misuse appears to be uncommon (Harrison et al., 2001).

Throughout the general literature on injury prevention, a decrease in injury rates (as reported by hospitals, health care workers, police, etc.) is the main performance indicator. This indicator is quantitative and relatively objective, but is not an ideal measure of achievements, as many injuries go unreported. Therefore, these rates, alone, may be quite misleading.

There have been numerous responses recently to the injury prevention challenge of how best to combine available models and then demonstrate their effectiveness. One of the most notable is a multi-modal approach developed by a Queensland Indigenous community with the collaboration of the University of Queensland and Queensland Health (Shannon et al., 2001). The project proposed an approach for injury prevention that effectively combines the community development model for improving wellbeing in Indigenous communities with the epidemiological model of injury control. This particular program explored the wide range of issues involved in initiating and developing a community owned, multi-modal program for the reduction of injury in Indigenous communities.

An important focus in the area of injury prevention is on the risks of road accidents and road-related injuries in Indigenous communities. These risks have been addressed by awareness campaigns (such as the Aboriginal Community Road Safety Project (Ella, 1992)), and the introduction of new laws (for example, Open Load Space Project (Cercarelli & Cooper, 2000)). A decrease in road injuries and deaths as a result of riding in open load spaces of vehicles and positive changes in Aboriginal community attitudes, knowledge and understanding of road safety issues have been major achievements of these interventions. Indigenous communities have welcomed these projects and are keen for them to continue.

With alcohol being a major contributing factor to many injuries in Indigenous communities, a reduction in the incidence of alcohol-related injuries and offences is a frequently used performance indicator. A reduction in injury rates, hospitalisation and engagement with the criminal justice system were achievements/performance indicators of programs that aimed to reduce the impact of problems arising from self-harm and interpersonal violence in rural and remote WA (by the availability of sobering up shelters, for example (Bellottie & Boas, 2000)). In the first year of operation of the sobering-up shelter in Wiluna (WA), there was a 33% reduction in alcohol-related injuries, a 90% reduction in arrests for damage offences, and a 67% reduction in arrests for assaults (Bellottie & Boas, 2000).

The Kowanyama Community Justice Group, which aimed to deal with juvenile perpetrators of violence in a culturally sensitive and community approved way, resulted in a one-third reduction in the numbers of juveniles appearing before the courts over 3 years (Harrison et al., 2001).

There are, of course, performance indicators which are very difficult to measure quantitatively, but which can still be seen as worthwhile achievements and indicators of a successful intervention. An example is the Woorabinda pub intervention, which has had substantial positive social benefits for the community (Canuto, Craig, McClure, Young, & Shannon, 2000). With the pub closed on Sundays, it is now becoming known as family day within the community.

Summary

The reasons for the greater incidence of injury among Indigenous people are complex, with the interaction of socioeconomic disadvantage, alcohol consumption and high-risk environments being poorly understood. Injury incidence, like other indicators of Indigenous health, primarily reflects broader social and economic factors, but there is scope for improving the health of Indigenous people by specifically targeting the problem of injury (Shannon et al., 2001). A clearer understanding of the variation in injury rates between different Indigenous communities and the importance of injury to those communities is required in order to form a firm basis for developing more effective injury prevention strategies.

As with other areas under investigation within the current review, current data sources are generally inadequate for: assessment of trends; identification and quantification of most risk factors; evaluation of the efficacy and other properties of most interventions; and assessment and monitoring of the extent and distribution of these interventions. On the other hand, a common theme of successful programs in the area of injury is that community control and ownership are important components in their success.

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Disability

Background

The concept of disability in Aboriginal and Torres Strait Islander populations is complex due to cultural interpretations of meaning and causation. There is a growing understanding of historical, social, spiritual and philosophical influences on Indigenous perceptions of disability and improvements in legal and human rights for all Australian people with disabilities.

Disabilities originate from a variety of factors and the risk of having a disability increases with age. Disabilities may result from: disorders that: are present from conception; occur during pregnancy; occur during the birth process or shortly before (perinatal); or occur in infancy or later life (Annison, 1996; Australian Indigenous Health*InfoNet*, 2001b). The impact on a person is also relevant to the stage of life when the disability occurs (for example, sensory impairments which occur following a period of normal development have consequences that are different from those that occur when disability is present from birth). From primary, secondary and tertiary preventive perspectives, interventions for reducing disability risk factors need to focus on the aetiology and the timing of causal factors. The following categories demonstrate the multiple risk factors for disability:

Prenatal or congenital

chromosome or genetic disorders

Prenatal environmental influences

malnutrition – associated with malformation of the foetus and growth retardation

exposure to drugs, toxins and teratogens:

marijuana – associated with low birthweight (a risk factor for disability)

alcohol – associated with Foetal Alcohol Syndrome and Foetal Alcohol Effect

smoking -associated with low birth weight (a risk factor for disability)

Maternal infection:

rubella – associated with multiple abnormalities of the foetus

herpes virus – associated with abnormal foetal development

syphilis – associated with intellectual disability

AIDS – possible association with facial deformity, risk of infection and failure to thrive

Maternal environmental influences

radiation – associated with microcephaly, malformations of the eyes, extremities and intellectual disability in the foetus

Perinatal influences

mechanical injury – depends on extent of damage. Usually associated with a narrow pelvis in the mother or malpresentation of the foetus

Perinatal asphyxia-

affects blood circulation and can result in damage to the central nervous system. Can result in cerebral palsy

Postnatal causes

injury from accidents or abuse – depends on extent of damage

ingestion or inhalation of poisonous substances

infections – damage depends on precise cause and treatment

meningitis

encephalitis

Compiled from (Annison, 1996)

There have been few studies of disability in the Indigenous population, but the prevalence of disability would be expected to be higher than in the general population because of the higher rates of disabling conditions (Australian Indigenous Health*InfoNet*, 2001a). Studies that have been carried out have found higher rates of disability than in the non-Indigenous population (Australian Bureau of Statistics, 1998; Hoy, Norman, Hayhurst, & Pugsley, 1997; Thomson & Snow, 1994), but statistics probably underestimate the degree of disability in the Indigenous population. This has implications for the provision of disability services.

Throughout their lives, many Indigenous people are at greater risk of exposure to many of the factors for disability than are non-Indigenous people. There is however, evidence of progress in minimising risk factors as demonstrated in this review in specific health areas.

Information about Indigenous people's use of disability support services is provided under the Commonwealth-State Disability Agreement (CSDA). There is overlap between disability services and aged care services, but CSDA funded services are generally aimed at people under the age of 65 years (Australian Institute of Health and Welfare, 2000). Indigenous people made greater use of community care services at younger age than did the rest of the population. Research on demographic patterns for Aboriginal people identify that the demands placed on fewer fit adult members of the Aboriginal population have to be taken into account when considering carers for people with disabilities (Wolstenholme, 1996). A number of barriers have been identified for Indigenous people with a disability in accessing assistance. For some families caring for a person with a disability, there has been reluctance to access services as they have feared a loss of culture for the person with a disability who may be removed from their community (Australian Bureau of Statistics, 1998). Valuing needs and concerns are necessary in refining health systems to be more responsive and accountable.

Recent developments

Policies protecting rights and enforcing anti-discrimination practices have contributed towards progress. There have been improvements for Indigenous people in acknowledgment of their diversity and their differences in ability to access services. The experience of disability is unique to each person, even though there are common impacting factors. The identification of these has been important for providing support, in creating understanding and for minimising marginalisation. There is evidence in the literature of actions to:

- address the circumstances that create risk factors;
- improve access to services and financial assistance;
- provide culturally sensitive interventions;
- provide advocacy; and
- establish networks of people with an interest in Indigenous disability.

Achievements

The limited information available on disability among Indigenous people has meant that it has been necessary to direct attention to accumulating qualitative and quantitative data. A workshop in April 1998, which brought together representatives from government departments, NACCHO, Aboriginal medical services and researchers in the field, addressed issues relating to the availability and quality of data relating to disability among Indigenous people (Australian Bureau of Statistics, 1998). Recommendations from the workshop included: the refinement of existing health and access indicators; conducting focus groups; and the development of services appropriate for Indigenous people.

Prior to the workshop, the Disability Data Reference and Advisory Group had been established in 1996 to advise the Australian Institute of Health and Welfare on improving, harmonising and standardising data collections in general. It also advised and promoted consultation as an Australian reference group regarding definitions for the World Health Organization's International Classification of Functioning, Disability and Health (known as ICIDH-2) which provides an international standard for the description of health and health related states (Australian Bureau of Statistics, 1998).

Working with Indigenous peoples with Disability (Centre for Remote Health, 2001) is a website (URL: http://www.wired.org.au/) that provides information about a wide range of practical resources for allied health professionals and carers working with Indigenous peoples with disabilities living in remote areas of Australia. It includes content on networks, resources, equipment, related sites and a bibliography.

There are moves to create understanding of the meaning of disability for Indigenous people in a holistic sense within the context of day-to-day life, socially, in work issues and in relationships with the environment. This creates a working platform for Indigenous people with a disability, their carers and health services. Themes within Indigenous cultural interpretations of disability have been identified, they include, objections to being 'categorised' and the disabling health effects of colonisation (Australian Bureau of Statistics, 1998). In his research with the Anangu people, Ariotti revealed Indigenous perceptions of disability (including spiritual), which have assisted in creating understanding (Ariotti, 1997).

Advocacy, participation in decision-making and overcoming barriers are areas highlighted by the Aboriginal and Torres Strait Islander Commission and National Disability Advisory Council Joint Working Party. The Working Party was established by placing notices in specialist media inviting people to nominate as members to provide advice to the Government on establishing a National Indigenous Disability Network. A panel of representatives from the Aboriginal and Torres Strait Islander Commission (ATSIC), the National Disability Advisory Council (NDAC) and the Office of Aboriginal and Torres Strait Islander Health selected 13 Indigenous members. The Working Party provides a 'voice' for Indigenous people with disabilities with the aim of improving access to medical services, transport, housing, education and employment, to increase resources and to create understanding of cultural and lifestyle differences (Aboriginal and Torres Strait Islander Commission and National Disability Advisory Council Joint Working Party, 2000).

A related achievement was the provision in 2000 of funds by the Commonwealth for an Indigenous disability advocacy pilot service in New South Wales (Anthony, 2000). The service was set up to explore innovative ways of delivering disability services to Indigenous communities across NSW, and to be available as a specialist resource for generalist disability services.

There are examples of successes in the design of equipment for Indigenous people with a disability. Disability aids are often designed for an urban lifestyles and not for sandy, rocky and uneven terrain. Examples include a low tilting table and back support for an Aboriginal artist with a back problem (Heath, 1995) and a bush wheel chair which has been developed to cope with rough terrain (Land, 1993). There is a need for users to work with inventors and manufacturers to make appropriate devices to fit in with lifestyle for Indigenous people.

There are indications of improvements for Indigenous people with disabilities, mainly in the area of understanding their needs. Ideally the minimisation of risk factors for disability would be the goal, as many disabilities are preventable. Other steps to address gaps would be to increase knowledge about services for those with a disability, provide more opportunities for early screening services (including in remote areas) and to overcome barriers in accessing services.

There are various interventions described in relevant sections of this review that address risk factors for potentially disabling conditions (such as diabetes and cardiovascular diseases). Improvements in screening provisions assist in identifying Indigenous people at risk of disability (for example, eye and ear health checks for school children can identify early stages of disease). Prompt treatment can make a difference to quality of life by preventing long-term damage that would impact on education and employment opportunities. As also detailed in this review, the employment of Indigenous people in health services has improved access and increased the potential of early presentation for illness.

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7 Summary

7.1 Introduction

The literature reveals achievements in Indigenous health over the past decade across a variety of areas, including improvements in some:

- health outcomes;
- process indicators with proven links to better health outcomes;
- areas of the health system or components thereof; and
- other areas (such as education, employment and housing) that are known to lead to improved health and wellbeing.

In considering achievements in Indigenous health over the past decade, however, it is worth reflecting on the goal set by the Commonwealth in 1973 of raising 'the standard of health of the Aborigines[46] of Australia to the levels enjoyed by their fellow Australians' (Commonwealth Department of Health, 1973, cited in Australian National Audit Office, 1998, p.124). This goal was to be achieved within 10 years. The current goal, as expressed in OATSIH's vision, is much more modest (and realistic): 'to raise the health status of Aboriginal and Torres Strait Islander peoples' (Office for Aboriginal and Torres Strait Islander Health, 2000). OATSIH recognises also that 'improving the health of Aboriginal and Torres Strait Islander people will take time'.

The change in expectations since the early 1970s reflects the greater understanding, generally, of the complex interaction of socioeconomic, cultural, environmental and personal factors (biological and behavioural), and the nature and availability of health services in determining health outcomes (Australian Institute of Health and Welfare, 2000; World Health Organization, 2000). In view of the continual overall improvements in the health status of the total Australian population (Australian Institute of Health and Welfare, 2002), it is likely, however, that not all Australians understand the complexity of achieving positive health gains for specific sub-populations. This lack of understanding may lead to unrealistic expectations of the gains in health status that can be expected in the short-term.

Realistic expectations of achievements in Indigenous health are based on:

- an appreciation that health depends on a complex interaction of socioeconomic, cultural, environmental and personal factors, and the nature and availability of health services;
- an understanding of the link between specific programs and/or interventions and health outcomes, and
- the extent of these programs and interventions in relation to health needs.

The complexity of the first aspect is reflected in recent attempts to refine the assessment of achievements in the health sector (see Sections 3.1 and 3.2).

The second of these aspects involves an appreciation of the variable lead-time required between the operation of a program, project or intervention and the realisation of the outcome of interest (see Section 3.3). In some instances, the time period between operation of the program, project or intervention and the health outcome may be of short or medium duration. For most health conditions, however, the lead-time between program, project or intervention and outcome is long and/or uncertain. The relationship between health outcomes and aspects like health policy, education or employment, while recognised, are even more complex, and the lead-times very uncertain.

As noted also in Chapter 3, concerted government efforts addressing Indigenous health disadvantages are relatively recent, with Commonwealth efforts really dating only from the mid 1990s. Recent levels of government funding for Indigenous health have been judged by

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[46] At that time, the term 'Aborigines' was used to include both Australian Aboriginal people and Torres Strait Islanders.

the CGC to be only about half those required, with the funding of 'up-stream' areas also less than needed.

These factors, combined with the often long and uncertain lead-times between the operation of programs, projects or interventions and the realisation of positive health outcomes, mean that it is unrealistic to expect that substantial gains in health status of Indigenous people will have been achieved in the relatively recent time period since government efforts started to move towards the levels required.

7.2 Summary of achievements

The principal aim of Indigenous health programs and services is to improve the health status of Indigenous people, so the achievements summarised here are presented generally in reverse order to their consideration in the substantial chapters of this report.

Improvements in health outcomes or in process indicators with a proven link to better health outcomes

Bearing in mind the issues discussed above with regard to the often long and uncertain lead-times for the achievement of positive outcomes, and the relatively recent increases in government responses to Indigenous health, examples of achievements include:

- community participation in the promotion of **physical activity** (to assist in the prevention of diabetes and cardiovascular disease, for example) has also produced social and emotional benefits for Indigenous people;
- improved dietary patterns as a result of **nutrition** programs. Increased consumption of fruits, vegetables, wholemeal bread, fruit juices and decreased intake of sugars and carbonated soft drinks provide the foundation for reductions in obesity and diabetes; community concerns about availability of healthy foods has resulted also in intersectoral action to increase the provision of healthy foods in remote community stores;
- multi-strategic approaches, incorporating the knowledge and involvement of individuals and communities, have been used in addressing **alcohol abuse, cigarette smoking, illicit drug use** and **petrol inhalation**. Dealing with these issues has involved collaborative actions with initiatives from Indigenous communities (such as in education programs, lobbying actions, restrictions in access (to alcohol and petrol), patrols, and sobering up centres). Results have been demonstrated with some reductions in consumption levels, in increased awareness of 'new' issues (such as illicit drug use), and in ways to address the context of the unhealthy behaviours (such as through improved employment opportunities).
- programs focussing on **maternal and child health** have resulted in increased birth weights and medical interaction with mothers throughout the pregnancy, and increases in breastfeeding.
- substantial attention has been directed to the **mental health** of Indigenous people, and the review identified a number of encouraging programs. There are no data, however, with which to assess improvements in terms of morbidity and/or mortality;
- awareness of the degenerative forms of **cardiovascular disease**, its risk factors and issues of care is increasing among Indigenous health care workers, policy makers and Indigenous communities – it is ultimately through these efforts that significant declines in mortality and morbidity will be achieved;
- the development of a program for the prevention and management of **rheumatic heart disease**. The program focuses upon tertiary prevention, particularly compliance with long-term prophylactic medication, as well as access to the program.
- there have been reductions over the past 20 years or so in the impact of **respiratory infections** in childhood. The recent introduction of vaccination programs against **pneumococcal disease and influenza** offer great potential benefits for Indigenous children and at-risk adults. There is evidence of a reduction in the incidence of invasive pneumococcal disease in some parts of Australia, but, overall, it is too early for

substantial achievements to have been documented. On the other hand, **asthma** appears to have emerged as a major problem for many Indigenous children and adults;

- there has been substantial progress in addressing 'upstream' factors influencing the level and impact of **diabetes**. These factors include increasing attention to the disease, greater awareness and understanding among Indigenous people of the disease, its risk factors and complications, and the development of more appropriate and more accessible preventive and care services;
- development of specific programs and services – at State, regional and local level – addressing the needs of Indigenous people with **renal disease** (particularly end-stage renal disease (ESRD)); these developments have benefited from increased understanding of the epidemiology and treatment of ESRD among Indigenous people;
- greater awareness of **cervical cancer** among Indigenous women, and increased availability and uptake of appropriate screening programs;
- advances in the awareness of **breast cancer** as an issue – by Indigenous women and by Indigenous and non-Indigenous health professionals;
- some successful programs in the area of **ear disorders** have been implemented to treat existing cases of otitis media and prevent the long-term complications associated with hearing loss among Indigenous children, including collaboration between the health and education sectors; the data available suggest that the prevalence of otitis media has not been reduced over the past decade or so;
- in the area of **eye health**, the incidence and severity of trachoma has decreased generally, but inflammatory trachoma remains endemic in some remote communities of central Australia; other achievements in Indigenous eye health involve: the sharing of expertise; the employment of Indigenous health workers; the development of specialist eye health guidelines; the provision of funding and equipment to ensure better access to services (particularly in remote areas of Australia); the building of partnerships; and improvements in methodology and technology;
- some recent initiatives offer promise for improvements in the **oral health** of Indigenous people, but, generally, very little attention has been directed to this important health area;
- reductions in the notification of some **sexually transmitted infections**, largely in response to specially developed control and prevention programs;
- implementation of appropriate strategies for **HIV/AIDS** prevention and/or management including the development of culturally appropriate resources;
- a marked reduction in **hepatitis B** virus infection since introduction of vaccination programs (despite less than optimal responses to the vaccination among Indigenous infants);
- awareness of the emergence of **hepatitis C** virus as a significant health problem for many Indigenous people;
- reductions in rates of hospitalisation for **diarrhoeal disease and gastrointestinal infestations** among Indigenous children, largely as result of improved nutrition, better hygiene and reduced exposure to pathogenic microorganisms;
- a rapid decline in the incidence of invasive ***Haemophilus influenzae*** **type B** (Hib) disease in Indigenous children following the introduction of vaccination;
- development and implementation of specific guidelines for handling outbreaks of **meningococcal disease** in Indigenous communities, and enhanced surveillance for the disease;
- guidelines have been developed for community control of **scabies and skin sores**, and successful community initiated coordinated programs have occurred;
- a number of programs have resulted in reductions of certain types of **injury** among Indigenous people, but, as with many other areas, current data sources are generally inadequate for: assessment of trends; identification and quantification of most risk factors; evaluation of the efficacy and other properties of most interventions; and assessment and monitoring of the extent and distribution of these interventions;

- awareness of the needs of Indigenous people with a **disability** has increased, and attempts have been made to improve the data on needs and services. The establishment of a national Indigenous disability network should also contribute to progress in this area.

Improvements in the health system

The **Indigenous health infrastructure** has been strengthened with the establishment of new bodies (for example, the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH), the National Aboriginal and Torres Strait Islander Health Council, and the Office for Aboriginal and Torres Strait Islander Health (OATSIH)) and consolidation of the role of the Indigenous community-controlled sector (the National Aboriginal Community Controlled Health Organisation (NACCHO) and State/Territory affiliates). There have been increases in funding directed to Indigenous health, and the Framework Agreements provide for more coordinated decision-making. There have been moves also to provide evidence-based direction to policies and strategies.

The literature demonstrates improvements in **access to appropriate services**. Barriers to access have been identified and methods of addressing these have been implemented. Achievements include: expansion of Indigenous community-controlled health services; greater recognition of the role of Indigenous health workers and growth in their numbers; the coordinated care trials; the availability of interventions in appropriate settings; community consultation; community identification of needs; the active role of the community in their own health issues; development of partnerships and intersectoral action; adequate resourcing; culturally appropriate mainstream programs; and improved access to the Medical and Pharmaceutical Benefits Schemes.

The growing **Indigenous health workforce** is involved in various health sector areas, within mainstream and Indigenous community-controlled health services. Specific training courses have improved access for Indigenous people, and improved cultural understanding for non-Indigenous health workers. Variable progress in the various disciplines of the Indigenous health workforce – Indigenous health workers, managers, nurses, doctors and public health workers – has led to the development recently of a national strategic framework for workforce reform and consolidation.

Knowledge and information about Indigenous health has improved through: refining **health information systems;** emphasis on Indigenous-specific **research** and **ethics;** and **knowledge management.** The improved identification of Indigenous status (in censuses, and in the births and deaths registration systems and hospital utilisation collections, for example) and the increased availability of other information (such as from surveys) have assisted in the allocation of specific funding for strategies.

The establishment of the Research Agenda Working Group (RAWG) by the National Health and Medical Research Council (NHMRC) and OATSIH is contributing to the development of a strategic research capacity in Aboriginal and Torres Strait Islander health. There has been substantial growth also in the number of groups with considerable involvement in Indigenous health research, particularly Indigenous-governed research organisations.

Since the promulgation in 1991 of the NHMRC ethical guidelines, substantial progress has been made in their incorporation into the processes of institutional ethics committees across the country. Some progress has been made also in the development of guidelines for the use of health information collected as part of administrative data collections.

In terms of knowledge management for Indigenous health, there have been a number of significant achievements over the past decade. Not only has there been much more regular and comprehensive publication of information and knowledge about Indigenous health, but also the publication of reports on specific health topics and of clinical care guidelines. A number of these reports have been disseminated also via the Internet. The Internet is also the main means of dissemination of knowledge and information by the Australian Indigenous Health*InfoNet*, which has the potential to be a key element in a national knowledge strategy for Indigenous health.

Improvements in other areas (such as education, employment and housing)

There have been improvements in factors contributing to Indigenous health. The awareness of the relationships of **education**, **employment**, and **housing and environment** to health has deepened awareness of the needs for Indigenous people. Methods of overcoming disadvantages in these areas have included specific targeting and the creation of pathways to facilitate access. There has been increasing participation in education and employment, and establishment of working partnerships and intersectoral links. Indigenous involvement in housing design and workforce (building and maintenance) has meant that greater attention has been directed to making housing more suited to Indigenous lifestyles and has led to skill building and improved income.

7.3 Factors contributing to success

As noted in Section 3.4, key informants to the project's framework consultations commented on a number of factors that they considered as important contributors – or potential contributors – to success. Perhaps even more so than achievements themselves, however, the general literature is unlikely to pay close attention to these factors. This needs to be borne in mind in reading this section, which attempts to summarise the extent to which the factors were identified in the literature.

Role of the community

All major reports in recent years have stressed the importance of the Aboriginal community-controlled health sector in efforts addressing Indigenous health.

The House of Representatives Standing Committee on Family and Community Affairs' inquiry into Indigenous health, for example, noted the capacity of ACCHSs to deliver significantly better services than other options and recommended that 'the Commonwealth support increased community control of health services for Indigenous communities' and that 'the community having responsibility to determine the nature of that control' (House of Representatives Standing Committee on Family and Community Affairs, 2000). In a similar vein, the 2001 report of the CGC concluded that 'effective community control of services' and 'the expansion of community controlled services based on regional health plans' are important factors in improving 'access to and the effectiveness of primary health care services for Indigenous people' (Commonwealth Grants Commission, 2001).

As well as these general recommendations in support of the Indigenous control of health services, many reports in the literature identified the importance of community control and participation in the success of specific programs and/or interventions. These aspects have been referred to in the previous chapters of this report, so only a few examples are provided here:

- the implementation of effective and culturally appropriate initiatives in the areas of alcohol misuse and petrol inhalation;
- programs addressing STIs (such those on the AP Lands);
- interventions for the control of scabies and skin sores;
- injury prevention and control initiatives;
- nutrition programs and those addressing obesity and diabetes;
- interventions aimed at the 'epidemic' of serious renal disease (including the Tiwi program).

The role of community control, participation and involvement in decision-making is the most constant of the various factors contributing to the success of health services (including mainstream services), programs and interventions. It is recognised as crucial also in policy development, and in research and ethics.

Resourcing

The adequacy of resourcing can be considered at two levels - the extent to which the overall resourcing addresses needs in all areas related to Indigenous health and wellbeing, and the level and continuity of resources for specific programs and/or interventions.

The CGC inquiry concluded that recent levels of government funding for Indigenous health were, at most, about half those required (Commonwealth Grants Commission, 2001). And, as noted in Chapter 3, the inadequacy of spending on health services was matched with similar conclusions by the CGC about expenditure in a number of health-related areas – such as education, training, employment, housing and infrastructure.

Even in the presence of the persisting gross overall under-funding of Indigenous health and associated areas, it is true that substantial progress has been made in a number of areas. The many examples of progress include: better and more consistent funding of ACCHSs and their 'umbrella' organisations; improvements in access of Indigenous people to the MBS and PBS; targeted support for specific disease-oriented strategies (such as those for ear and eye disorders, diabetes, renal disease, sexual health, and rheumatic heart disease); and attempts to enhance service access through funds pooling under the Coordinated Care Trials.

The situation for individual programs and/or interventions is not clear, however, as obtaining reliable information from the literature is not straightforward. First, there is a tendency of managers of programs to report under-funding even when the funding is adequate for the agreed objectives. This may occur because of the tightness, but not inadequacy, of funding or where the manager recognises the potential beyond the agreed objectives. Second, adequate funding should not appear exceptional, but rather be expected for sound programs. In this case, comments on the level of funding may not seem necessary in any reports. And third, comments about the adequacy of funding may be confined to reports to funding agencies and not appear in the publicly available literature. It is not surprising, then, that relatively few reports in the literature comment on the adequacy, or inadequacy, of funding.

The overall situation for the operation of individual programs may not be clear, but there is little doubt that insufficient resources have been allocated for the evaluation of programs.

Sustainability

As noted in Chapter 3, key informants to the project's framework consultations identified appropriate resourcing – in terms both of levels and continuity – as a crucial aspect in the sustainability of programs, projects and interventions. Other important factors include staff changes, a failure to sustain behavioural changes, and changes in community priorities.

Apart from the inadequacy of overall funding, there was little in the literature about appropriate levels and continuity of funding. There was little in the literature also about failure to sustain behavioural changes, and changes in community priorities, but some reports noted issues related to staff changes. An example is the Fitzroy Valley Pap Smear Register and Cervical Screening Program, the coverage of which was not sustained as a result of staff and organisational changes. This report is quite exceptional, as it is far more likely that nothing will be written about programs that have not been sustained. This appears to have been the case with the Victorian Aboriginal Mental Health Network, which was seen as a major success in Victoria around 1990.

Partnerships, including intersectoral collaboration

The role of partnerships can be seen at all levels within the health sector, and between the health and other sectors. The importance of partnerships at grass-roots levels has been recognised for many years (National Aboriginal Health Strategy Working Party, 1989), but the importance attached also by the National Aboriginal Health Strategy Working Party to formal partnerships and intersectoral collaboration in policy and planning has only recently been acknowledged by Australian governments (Commonwealth Grants Commission, 2001). This acknowledgment is evidenced by the development of the Framework Agreements between Commonwealth and State/Territory health authorities, Indigenous community-controlled health organisations and ATSIC.

It will be some time before the full impact of these Framework Agreements can be assessed, but NACCHO has noted that they have contributed to: improved intersectoral communication and collaboration in several States and Territories; joint Indigenous health regional plans; and resourcing for NACCHO and most of its State/Territory affiliates (Commonwealth Department of Health and Aged Care, 2000).

More generally, the literature attests to the importance of partnerships in a number of ways. In the housing and environmental areas, in particular, effective partnerships were identified as very important – nationally and in a number of individual jurisdictions. Partnerships were seen as important also in Indigenous training and employment, both in the health sector and more generally.

Within the health sector, effective partnerships have been identified as contributing to the success of programs in the areas of nutrition, diabetes, alcohol and substance use prevention and treatment, STI prevention and control, and cancer screening. It is likely that effective partnerships have contributed to successful programs a variety of other areas also, but this aspect was not reported specifically in the literature.

Workforce issues

There has been increasing attention to the representation of Indigenous people in the workforce. This review focussed predominantly on developments in the health sector, but it is evident that employment opportunities generally are increasing, diversifying and becoming available at higher levels of the employment hierarchy. New opportunities in rural and remote areas – where many Indigenous people live – have been created in health, tourism, housing and mining. Addressing the under-representation of Indigenous people in the workforce has positive implications for their generally low socioeconomic status and its associations with poor health. Initiatives recently have led to the development of pathways between education and employment, particularly for young people who should now find the transition easier. Attention has been given also to increasing Indigenous participation in tertiary education and further linking that with a growing number of employment networks. Indigenous identification in the monitoring of retention rates in education and employment will assist in a more accurate picture of achievements.

There have been significant increases in participation in training and employment for Indigenous health workers, doctors and nurses and researchers. Recognition of their vital role in health services to Indigenous people has led to improved recruitment and retention strategies, and attention to career structures, role definition and skill recognition.

Recruitment of Indigenous people has increased the accessibility of the health system to Indigenous people, promoted cultural awareness and contributed to more effective liaison with mainstream services.

Evaluation

The views of key informants – that the evaluation of programs and interventions in Indigenous health is only just beginning to take place – appears consistent with the literature. Very few of the programs and projects included in this review appear to have been subjected to rigorous, formal evaluation.[47] This conclusion is supported by a number of other reviews, including those of programs in the areas of alcohol use (Gray, Saggers, Sputore, & Bourbon, 2000; Gray & Sputore, 1998), tobacco use (Ivers, 2001),and physical activity (Cairnduff, 2001).

As noted by the key informants, an evaluation strategy should be a requirement of program/project planning, and adequate resources should be allocated as part of the program/project budget.

Accountability

There are increasing demands across health systems for accountability, as evidenced by the greater emphasis on performance indicators – nationally and for specific sub-populations, such as Aboriginal and Torres Strait Islander people.

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[47] This is, of course, the case with nearly all health programs and projects everywhere – particularly those programs 'proven' to be successful in other contexts.

As noted by the National Aboriginal and Torres Strait Islander Health Council, investing in Indigenous health must lead to real and sustained long-term improvements which can be demonstrated – to Indigenous communities, and to investors (National Aboriginal and Torres Strait Islander Health Council, 2000). This implies a need for monitoring the effectiveness of programs, and the evaluation of policies and programs that are designed to improve the status of, and service delivery to, Indigenous people. There is an emphasis on evidence-based approaches to policy and program development, a growing demand for high quality Indigenous knowledge and information (including time series on health status and social conditions) and for comprehensive performance indicators.

Another area of accountability is that of non-Indigenous (and Indigenous) researchers to the communities with which they work. Recent developments, with ethical considerations paramount, have refined the process – to increase community control and incorporate Indigenous culture and values, and, thus, improve the likelihood of benefits to the community.

In turn, Indigenous organisations have worked with governments on the development of more consistent service reporting. The Service Activity Reporting (SAR) questionnaire, which is collected by OATSIH under the terms of funding agreements with ACCHSs is, for example, a joint activity with NACCHO.

Overall, recent developments in the area of accountability should contribute to health system improvements, and, thus, achievements in Indigenous health.

Capacity building

The literature documents many examples of capacity building in the skills, knowledge, and confidence of Indigenous organisations, communities, families and individuals. This has contributed to increases in Indigenous self-determination, participation in decision making, and representation at management levels, as well as greater influence at regional and community level.

Greater respect has been given generally to Indigenous culture, languages, views of health, traditions, and priorities, thus enabling more appropriate health interventions. Creating networks and giving Indigenous people a 'voice' (in disability issues, for example) has facilitated greater understanding of complex issues.

Increased support for ACCHSs and other Indigenous organisations not only enhances the availability of services, but also contributes to education, training, employment, achievement and pride (National Aboriginal and Torres Strait Islander Health Council, 2000).

Examples of increasing community capacity can be demonstrated in programs for nutrition, control of alcohol and petrol abuse, and in promoting physical activity. At the family level, building capacity has been addressed in projects such as the Port Augusta Families Project, suicide interventions, and in relocation of services for renal care and disabilities (so that families are able to take more active roles in caring).

For individuals, examples of improvements can be demonstrated for behaviour management, skill development, and increasing knowledge within a variety of health issues. The concept of inter-generational capacity building has been utilised in programs which have valued traditional and cultural practices and the knowledge and experiences of older members of the community. Examples include diabetes programs (where adults have assisted children in making healthy nutritional choices) and an emphasis on community women as role models for advice and support in infection control and maternal health.

These examples of capacity building – at organisational, community, family and individual level – confirm the importance attached to this area by the National Aboriginal and Torres Strait Islander Health Council and the CGC.

7.4 Conclusion

In view of Australia's performance in health generally - and the country's wealth - improvements in Indigenous health outcomes over the past decade have been disappointing.

It is important, however, that these improvements should be viewed in the context that concerted efforts addressing the enormous health and other disadvantages experienced by Indigenous people began less than a decade ago. And even these efforts have been deemed by the CGC to be much, much less than is required. In the area of health services alone, the Commission recommended at least a doubling of current government expenditure.

The fact that these less-than-optimal government efforts began so recently also limits what can be expected in terms of the translation of programs, projects and interventions into health outcomes. As noted above, the importance of factors 'up-stream' to health, and the often long and uncertain lead-time between the operation of programs, projects and interventions and the realisation of positive health outcomes, means that it is unrealistic to expect that substantial gains in health status of Indigenous people will have been achieved in the past decade.

If allowance is taken for these factors, the assessment of achievements in Indigenous health is much more encouraging.

For a start, it is encouraging that governments have started to move towards the level of commitment required to achieve equitable health outcomes for Indigenous people. This move can be seen not only in the considerable increase in expenditure since the mid 1990s, which has assisted in increasing the availability of community-controlled services and in the growth and development of NACCHO and its affiliates, but also in improvements in the health infrastructure.

Examples of the improvements in the health infrastructure are the Framework Agreements, the establishment of the National Aboriginal and Torres Strait Islander Health Council, and the strengthening of inter-governmental mechanisms (with the establishment of the Standing Committee on Aboriginal and Torres Strait Islander Health, which supersedes the Heads of Aboriginal Health Units forum).

Accompanying these improvements in the health infrastructure are: improved access of Indigenous people to mainstream services (including the Medical and Pharmaceutical Benefits Schemes); growth in the Indigenous health workforce; greater availability of Indigenous health knowledge and information; and the development of a strategic research capacity in Indigenous health (particularly through establishment of the Research Agenda Working Group).

There have been some improvements also in 'up-stream' factors of importance to health, such as education and housing. But, as is the case with health, the CGC recognised that much, much more needs to be done in these and other areas.

In terms of health outcomes, there appears to have been little improvement, if any, in recent years in some key health indicators (such as expectation of life and the infant mortality rate), but there is evidence of increased birth weights in response to specific programs. There is little evidence also of any real improvements in the overall levels of the major chronic health conditions (such as heart disease, cancer, diabetes and renal disease), but substantial improvements have been documented for a number of communicable diseases, at least in some areas. These include invasive pneumococcal disease and other respiratory infections, inflammatory trachoma, some sexually transmissible infections, hepatitis B virus infection, diarrhoeal disease and gastrointestinal infestations among Indigenous children, and invasive *Haemophilus influenzae* type B (Hib) disease.

In terms of process indicators with proven links to better health outcomes, there are some encouraging signs in the areas of physical activity and dietary patterns.

As well as the overall improvements in the health system summarised above, there has been substantial progress in a number of the system components. These include programs focussing on maternal and child health, initiatives in the area of substance use, the development of a variety of disease-specific programs (for renal disease, ear disorders, and skin conditions, for example), and injury prevention and control strategies.

Of the various factors identified by key informants in the consultation phase of the project, the literature review confirmed the important roles of the community (in terms both of community control and participation) and of partnerships. As noted above, resourcing was recognised as crucial at an overall level. It was not possible to discern from the literature, however, any clear picture of the resourcing of individual programs - except that insufficient resources have generally been allocated for evaluation - or of issues relating to sustainability. The importance of capacity building, emphasised by the National Aboriginal and Torres Strait Islander Health Council and the CGC, was clear from the literature. Encouraging developments have occurred in the Indigenous workforce, and in accountability mechanisms.

In summary, improvements in health outcomes for Indigenous people over the past decade have been disappointing in a country with the wealth and standards of living like Australia. Overall, however, achievements in Indigenous health are encouraging. In assessing achievements, allowance needs to be made for the fact that the bulk of them have never been written up for publication, the recent nature and level of government commitment, and the complex interaction between factors 'up-stream' to health, health programs and interventions, and specific health outcomes. In this context, there are clear achievements in building health infrastructure, access to appropriate health services, the Indigenous health workforce, improved knowledge about Indigenous health, and gains in specific program areas.

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Appendix: Achievements in Aboriginal and Torres Strait Islander Health Project

The project was commissioned from the Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) by the Office for Aboriginal and Torres Strait Islander Health (OATSIH) on behalf of the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH - a subcommittee of the Australian Health Ministers' Advisory Council). The project aimed to document and share information about achievements in Indigenous health over the past decade, and to use this information to promote and build on the experience of health services, programs and strategies that have been shown to work.[48] The scope of the project included primary, secondary and tertiary health care, as well as relevant programs in non-health sectors, such as housing and education. It is anticipated that the knowledge gained during the project will be used also to inform future initiatives.

The project consisted of three phases:

- Phase 1 – an initial literature review, parallel consultations and additional information gathering in order to provide a framework for the more detailed data collection phase. This first phase focused attention on evidence in the literature that would inform the framework developed for the collection, in Phase 2, of information about successful programs. As part of the consultations, key informants assisted in the development of a working definition of success (or achievement), and identified a number of factors believed to contribute to success.
- Phase 2 – State and Territory health authorities and non-government health services were asked to identify successful programs and provide data to the research team utilising the framework developed in Phase 1. During Phase 2, the project team worked with SCATSIH members, who had the vital role in facilitating, coordinating and advising on the collection of information by their jurisdictions. In parallel with this data collection, the literature review was largely finalised and a draft report prepared.
- Phase 3 – this phase involved a critical analysis of the collected data examining successful programs and factors that had been identified as contributing to their success, and the production of a final project report. Achievements were categorised according to a matrix combining 'area of achievement' and relevant sector. Area of achievement includes aspects such as access to services, community control, environmental conditions, and social and economic measures, as well as specific health conditions (for example, cardiovascular disease, mental health, injury, and cancer). The relevant sectors are primary health care; secondary/tertiary health care; health infrastructure; and other sectors (such as education, housing, employment, community and welfare).

The working definition of success (or achievement) used by this project, which had emerged from the project framework consultations, was:

> A success in Indigenous health is a program, project or intervention, or element thereof, that produces, or could contribute to, a demonstrated improvement in Indigenous wellbeing. This may be measured by an improvement in health outcome, other health indicators or in other process or infrastructural indicators.

The factors to be considered in assessing success were: role of the community, resourcing, sustainability, partnerships (including intersectoral collaboration), workforce issues, evaluation, accountability, and capacity building.

Project management structure and project roles

The Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) was appointed to conduct the project. The project team consisted of:

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[48] For a complete description of the project, see Shannon, Wakerman, Barnes, Hill, & Griew, 2002

- Associate Professor John Wakerman, Director of the Centre for Remote Health, who managed the project on behalf of the CRCATH;
- Associate Professor Cindy Shannon, assisted by Condy Canuto, an Indigenous epidemiologist, and a team from the University of Queensland, was responsible for the substantive components of the project, including consultations with key stakeholders; developing the framework; leading and managing the data collection about successful programs; critical analysis of case studies; and production of the final project report;
- Professor Neil Thomson and the Australian Indigenous Health*InfoNet* team, was responsible for the literature review;
- Professor Tony Barnes (CRCATH), Dr Peter Hill (University of Queensland), Dr David Thomas (CRCATH) and Robert Griew provided expert guidance and contributions to the critical analysis.
- Ann Ritchie provided expert editorial input.

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