Political Visions: Blindness Prevention Policy as a Case Study of Community–Government Relations in Aboriginal Health

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VicHealth Koori Health Research and Community Development Unit

Discussion Paper Series

The VicHealth Koori Health Research and Community Development Unit (VKHR&CDU) was launched in June 1999 and has been developed in partnership with the Victorian Aboriginal Community Controlled Health Organisation, the Victorian Health Promotion Foundation (which funds the Unit) and the University of Melbourne through the Centre for the Study of Health and Society where the Unit is located.

At the core of the Unit's work is a commitment to undertaking, collaborating in and supporting research that directly benefits the Koori community. The work of the Unit spans academic and applied research, community development, and medical education. The combination of these activities is a central and innovative aspect of the Unit's function, as is the identification and use of mechanisms to link research with the improvement of health care practices and policy reform. Overall, these tasks are guided by both an Advisory Committee and a Research Advisory Group.

In relation to the research program, five key areas govern the inquiry undertaken within the Unit. These comprise: historical research into Koori health policy and practice; historical and contemporary research into health research practice, ethics nd capacity building; applied research on the social and cultural experience of Koori health, well-being and health care delivery; health economics research on the factors and processes that impact on the provision and use of Koori health care; and the evaluation of Koori primary health care and related health promotion programs.

The Discussion Paper Series (DPS) is directly linked to this diverse program of research and provides a forum for the Unit's work. The DPS also includes papers by researchers working outside the Unit or in collaboration with VKHR&CDU staff. Individual papers aim to summarise current work and debate on key issues in Indigenous health, discuss aspects of Indigenous health research practice and process, or review interim findings of larger research projects. It is assumed that the readership for the series is a broad one, and each paper is closely edited for clarity and accessibility. Additionally, draft papers are 'refereed' so as to ensure a high standard of content.

More information on the series, on the preparation of draft papers, and on the work of the Unit can be obtained by directly contacting the VKHR&CDU.

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Foreword

The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) is the peak body for Aboriginal community-controlled health services in Victoria, representing twenty-seven member organisations. Most VACCHO members are multi-functional community organisations with health as a key part of their responsibility and some offer full health services. VACCHO's mission is to improve Victorian Aboriginal health by upholding the principles of local Aboriginal community control.

VACCHO has signed a Memorandum of Understanding with the VicHealth Koori Health Research and Community Development Unit (VKHRCDU) in recognition of the key role played by VACCHO in setting the agenda and providing advice to the VKHRCDU. This Discussion Paper is one outcome of our ongoing partnership.

Nili Kaplan-Myrth was a visiting scholar at the VKHRCDU for twelve months during 2001–2002. Nili chose to spend a year in Victoria, looking at Aboriginal health policy in general, and blindness prevention as a specific case study. Nili was enrolled in a PhD in the Department of Anthropology, Yale University, and was supported by a Fulbright Graduate Fellowship (US–Australia). She returned to the US and then to Canada in 2002, completed her studies and was awarded her PhD late in 2003.

While in Victoria, Nili offered her services to VACCHO and worked in a voluntary capacity to provide research and policy advice and support to VACCHO staff and VACCHO member organisations. She contributed to the training of Aboriginal Health Workers, travelling with VACCHO staff and with her family to visit many Aboriginal community organisations and to provide tutoring to Aboriginal Health Workers enrolled in training through VACCHO.

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Acknowledgments

This discussion paper is written as a report for the Aboriginal and non-Aboriginal people who work in Victoria and across Australia with steadfast commitment to improving Aboriginal health.

It was an honour to earn the trust and support of those who made my year in Australia a productive one. I owe particular thanks to Ian Anderson and his colleagues at the VicHealth Koori Health Research & Community Development Unit, and Jill Gallagher and her colleagues at the Victorian Aboriginal Community Controlled Health Organisation.

The material in this paper is based on twelve months of research that I conducted in 2001 to fulfil the requirements of a doctoral degree in the Department of Anthropology, Yale University. The research was supported by a Fulbright Graduate Fellowship (US–Australia).

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Political Visions: Blindness Prevention Policy as a Case Study of Community–Government Relations in Aboriginal Health

Summary

All health policy is political. In this paper I use Aboriginal eye health policy processes as a lens through which to study collaborative relationships between Aboriginal community-controlled health organisations and governments. I trace the history of Aboriginal eye health programs in Australia from the missionary visions of Dr Fred Hollows to present-day blindness prevention initiatives in rural Victoria. The questions I address are: Who sets public health priorities? How do Koori communities participate in Aboriginal eye health? How is self-determination negotiated in Aboriginal health policy and programs? These issues are highlighted through the words of Koori Elders, hospital liaison officers, health service coordinators, Health Workers, nurses, doctors, ophthalmologists, optometrists, Aboriginal and non-Aboriginal students and health researchers, representatives from the Victorian and National Aboriginal Community-Controlled Health Organisations, bureaucrats and elected officials in the Office for Aboriginal and Torres Strait Islander Health (OATSIH), the Aboriginal and Torres Strait Islander Commission (ATSIC), the Department of Human Services Victoria (DHS), and in the Australian Parliament.

Abbreviations

ACCHS	Aboriginal Community-Controlled Health Service(s)
AMS	Aboriginal Medical Service(s)
ANCARD	Australian National Council on AIDS and Related Diseases
ATSIC	Aboriginal and Torres Strait Islander Commission
CERA	Centre for Eye Research Australia
DHS	Department of Human Services (Victoria)
MSOAP	Medical Specialist Outreach Assistance Program
NACCHO	National Aboriginal Community Controlled Health Organisation
NIDDM	Non-Insulin Dependent Diabetes Mellitus
OATSIH	Office for Aboriginal and Torres Strait Islander Health
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VKHRCDU	VicHealth Koori Health Research & Community Development Unit, University of Melbourne
WHO	World Health Organization

Political Visions: Blindness Prevention Policy as a Case Study of Community–Government Relations in Aboriginal Health

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Introduction

All health policy is political. Out of an interest in the critical anthropology of health (Singer *et al*. 1990), I travelled to Australia in 2001 to analyse contemporary relationships between Aboriginal communities and government in the development of eye health policy and programs. This paper is based on that research (Kaplan-Myrth 2004).

Working primarily in Melbourne with VACCHO, I interviewed key stakeholders in the Aboriginal community-controlled health sector, including Koori Health Workers, hospital liaison officers, nurses, policy analysts, executives of health services, health researchers, and Koori bureaucrats. I also interviewed non-Aboriginal bureaucrats and politicians in regional, State and Commonwealth government.

In this paper, I trace the history of Aboriginal eye health programs in Australia from the missionary visions of Dr Fred Hollows to present-day blindness prevention initiatives in rural Victoria. I then ask the following questions: Who sets public health priorities? How do Koori[1] communities participate in Aboriginal eye health? How is self-determination negotiated in Aboriginal health policy and programs? Although I conceal the identities of my interlocutors, throughout this paper I present Aboriginal and non-Aboriginal Australians' responses to those questions.

Blindness in the Australian Aboriginal Population

More than 90 per cent of the world's blind people live in the developing world (Thylefors 1998). Indigenous peoples in developed countries nevertheless suffer from rates of blindness comparable to those found in developing countries: 0.1 per cent of the non-Aboriginal Australian population is estimated to be blind; in contrast, 1 per cent of the Aboriginal Australian population is blind, a rate it shares in common with the populations of Indonesia, Nepal, Cameroon, Mali and Zimbabwe (Taylor 1997; Thylefors *et al.* 1995). The ten-fold disparity in the rate of blindness between

1 Koori is a term used to describe Aboriginal people from south-eastern Australia.

Aboriginal and non-Aboriginal Australian populations is a reflection of the generally low health status of Aboriginal Australians, and serves as an example of the extreme social inequalities in health in Australia (Comm. Dept of Health and Family Services 1997; National Aboriginal and Torres Strait Islander Clearing House 2000).

Aboriginal Australians are affected by a historically high rate of blinding trachoma and a rapidly increasing rate of non-insulin-dependent diabetic retinopathy (Graham 1996; Stocks *et al*. 1994; Taylor 1980). Trachoma—stigmatised as a disease of poverty, ignorance and dirt—is an infectious eye disease which progresses from a non-blinding conjunctivitis (in children under the age of five years) to a blinding stage known as trichiasis, when in-turned eyelashes permanently scar the cornea (in adults who have been in continuous contact with trachomatous children). Trachoma is spread by flies and human contact and can be prevented through improved hygiene and housing. Blindness due to trichiasis can be prevented through early detection and surgical treatment (WHO 1996). Trachoma is most prevalent in rural and remote communities, where there are crowded living conditions, a lack of access to clean water and inadequate waste-disposal facilities.

Non-insulin-dependent diabetes mellitus (NIDDM) is a chronic metabolic disorder in which the pancreas does not produce enough insulin to control the body's blood sugar level. This disease has become prevalent worldwide as populations have altered their diets. For example, whereas traditional Aboriginal Australian diets were high in protein and low in carbohydrates, Aboriginal people now eat processed foods that are high in refined carbohydrates and fat (NHMRC 1997). Uncontrolled diabetes causes damage to the blood vessels at the back of the eye leading to blindness. NIDDM can be prevented through proper nutrition and oral insulin supplements. Blindness due to diabetic retinopathy can be prevented through early detection and surgical treatment (Harper *et al*. 1995; Mitchell 1985). NIDDM is prevalent in urban, rural and remote Aboriginal communities. The *National Diabetes Report* indicates that Aboriginal Australians have rates of diabetes four times higher than the rest of the Australian population and that one third of Aboriginal Australians have diabetic retinopathy (NHMRC 1997). That report recommends that Aboriginal communities should be screened annually for NIDDM (Colagiuri *et al*. 1998).

The Status Quo: Mainstream Eye Care

Annual screening in every Aboriginal community across Australia? Unlikely, given the geographical diversity and remoteness of many communities, the logistics and the resources needed. Furthermore, like most health care, eye care is generally offered through mainstream clinics that are culturally inappropriate or inaccessible, sometimes even racially discriminatory (Briscoe 1991; Graham 1996; Resnicow *et al*. 1999; Stocks *et al*. 1994).

In conversations about their reluctance to seek preventive eye care, Kooris in rural Victoria express their wariness of mainstream eye health clinics:

> We totally rely on going to optometrists and ophthalmologists. People find that intimidating and don't attend their appointments. Which is why we need to be able to do it at the co-ops. *(Koori Elder)*

Ironically, many mainstream health practitioners are reluctant to care for Aboriginal patients because they are intimidated by Aboriginal people, possibly because they know their practices are tailored to a non-Aboriginal clientele, or just through lack of familiarity and ignorance about Aboriginal people, their culture and their needs. This cultural insecurity on the part of general practitioners and medical specialists exacerbates health inequalities (NACCHO 1997).

Aboriginal community-controlled health services attempt to recruit local specialists—ophthalmologists, podiatrists and others—in the hope that they will offer occasional clinics for Aboriginal clients. Unfortunately, they are sometimes forced to recruit ophthalmologists and optometrists from neighbouring towns because whoever is geographically closest to them refuses to work with the Aboriginal community. The directors of Aboriginal community-controlled health services have strategies to deal with these overtly racist practitioners:

> If I find an optometrist who won't deal with Aboriginal people and it is purely a race reason, I would be advising the Optometrists' College, for example, the Optometrists' Association, that one of their members has a problem and they need to do something about it before somebody else does something about it and he finds himself in court. That's one way to deal with it. The other is, 'Is this my role, to try and teach this person? Or will I go to the other optometrist who isn't an asshole?' I'll go down to the other one and leave this bloke to his devices. *(Health director of an ACCHS)*

Patient–practitioner interactions are not, however, the sole barrier to the success of health programs in Aboriginal communities. Inadequate infrastructure and resources are another significant cause for concern, with most Aboriginal community-controlled health services only equipped with the skills and tools to conduct rudimentary eye exams:

> How can you test people's eyes if you have no equipment? *(ACCHS executive director)*

The lack of capacity to run public health campaigns is yet another problem. Even if Aboriginal community-controlled health services are adequately resourced to provide basic ophthalmic care, they often do not have the expertise and resources to run public health campaigns in their communities. As a consequence, people who are at high risk for diabetic retinopathy are not aware of the need for eye care:

> It is nice to have these programs in our co-ops and whatever else. But if the community doesn't know about them, they're an absolute waste of time. We need money in our budgets for publicity: for making brochures about each individual program, posters for children's awareness about ear care, eye care, whatever. It is fine to

> have these wonderful programs, but if the people out there don't know, then what's the point? *(Koori eye health coordinator)*

Given the shortcomings of mainstream health services and Aboriginal communities' incapacity to provide their own specialist services, what can be done to address the high rates of eye disease in Aboriginal communities? In order to respond to this question, it is useful to review past Aboriginal eye health policies and programs.

Australian and International Eye Health Policy

Dr Fred Hollows—ophthalmologist, philanthropist and champion of the cause of Australian Aboriginal eye health—was commissioned in the mid-1970s by the Commonwealth government to report on the status of eye health in Australia.[2] Hollows found that 38 per cent of Aboriginal people showed signs of trachoma, compared with 1.7 per cent of non-Aboriginal Australians (Hollows 1973). Aboriginal eye health statistics were a source of considerable national and international embarrassment:

> There was a chap called Fred Hollows who you probably heard of. An ophthalmologist who decided to do something and he alleviated a lot of the trachoma issues in remote and northern Australia. As a result of that, I think it pin-pricked a lot of people into a bit of shame and embarrassment. They thought, 'We need to do something with eye health'. *(Non-Aboriginal ophthalmologist)*

In response to these statistics and more recent epidemiological studies, the Commonwealth government made several attempts to improve Aboriginal eye health. Australian blindness prevention policies drew closely on World Health Organization (WHO) strategies for blindness prevention.[3] In keeping with the WHO's *Alma Ata* declaration (WHO & UNICEF 1978) and the Commonwealth government's support for primary health care, blindness prevention policies emphasised public health education, the recognition of cultural factors affecting care, and community development (Torzillo & Kerr 1991).

What is primary eye care? Primary eye care, as it is defined by the WHO, aims to improve environmental conditions and to foster health care and education at the local level. Primary eye care is a component of the general model of community-based rehabilitation that promotes the use of community health workers in local health centres and draws on support from local healers and authorities (Brian & Hollows 1989; Carrillo *et al.* 1999; Ehiri & Prowse 1999; Ellwein & Kupfer 1995; Francis & Turner 1993; Hollows 1985; Kupfer 1994; Ladnyi & Thylefors 1983; Lynch *et al.* 1994; Mechanic 1999; Sommer 1989; Stilma *et al*. 1991; Thylefors 1990; WHO 1997).

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2 Dr Hollows was given the prestigious Order of Australia Medal (OAM) in 1981 for his work in Aboriginal eye health. He subsequently gave back his OAM out of frustration because he could not get the Commonwealth government to see what he thought was the reasonable way to proceed with eye care (Hollows 1991).

3 The close relationship between the World Health Organization and Australian eye health policy can be traced to ophthalmologists such as Dr Hugh Taylor who are commissioned to work at the national and international level.

More than twenty years after the initial promotion of primary eye care in the 1970s, it is still the dominant public health model for blindness prevention in Australia. The concept of primary eye care was raised in several of my conversations with Australian ophthalmologists and optometrists. Without exception, and somewhat to my surprise, they down-played the need for specialists with fancy gadgetry, emphasising instead the importance of skilled nurses and Aboriginal Health Workers:

> Ninety per cent of the eye conditions that present can be treated by removal of the foreign body, conjunctivitis, and that sort of stuff, that needs to be treated here and now… it does not need to wait two months for the next ophthalmologist visit, it does not need to be put on a plane and flown 2000 km to Perth to be examined. So there is the need to have at least the lower level eye skills in the community. *(Non-Aboriginal ophthalmologist)*

Government bureaucrats, eye specialists, and representatives from the Aboriginal community-controlled health sector agree that Aboriginal liaison officers and Health Workers greatly enhance patient–practitioner interactions. Health Workers and liaison officers play the roles of advocates for Aboriginal community members:

> If people like myself, Health Workers, could do the preliminary test, it would help break down the barriers and that fear-factor of having to go immediately to the outside world. Because we can explain the process thoroughly to them. That's half the problem. It's the fear of what's going to happen in that next stage when they actually do go to a professional. *(Koori Health Worker)*

Government health departments know that the skills, infrastructure and resources vary from one Aboriginal community-controlled health service to another. They therefore look for simple, inexpensive ways to run public health campaigns, the goal of which is to get health information out into Aboriginal communities:

> One thing we're looking at doing—both in the Aboriginal communities but also in mainstream—to raise the whole consciousness on the issue of vision and vision-loss, the need for regular exams and the identification of high risk groups. That involves complete community education; to raise awareness as one would have with drunk-driving, no alcohol and driving, smoking, the Quit campaign, so that people know vision is something that you can't take for granted. That needs to be information that gets through to all Aboriginal communities. *(Non-Aboriginal ophthalmologist)*

> For diabetic eye disease, you need to get information through to those people related to diabetes, so that is people with diabetes, their families, relatives, care personnel, about ten different professional groups who provide care for diabetes. All those people need to know the importance of diabetic eye disease and the need for regular examination. *(Non-Aboriginal ophthalmologist)*

Eye health coordinators tailor public health education campaigns across Australia to suit the different health priorities in the geographically dispersed Aboriginal communities:

> In communities without trachoma, they don't need to know anything about trachoma. But in communities with trachoma, you need to emphasise facial cleanliness on the one hand, and emphasise community environmental health improvement, and you need to have community involvement in terms of azithromycin distribution, particularly if you are out treating all the children or families or whatever… that is really something that has to be worked through the community, so they know and understand… There's a specific initiative being launched and ongoing in those areas. *(Non-Aboriginal ophthalmologist)*

Primary eye care is a grand idea, but is it effective? Irrespective of the World Health Organization and the Australian Commonwealth government's emphases on primary eye care and community-based rehabilitation, in practice most Aboriginal people still do not have access to any form of eye care.

Social scientists attribute the failure of primary eye care programs—and other public health programs—to top-down policy processes that neglect the social and political dimensions of illness and healing (Courtright 1995; Jaffré & Moumouni 1993; Lane & Meleis 1991; Lane *et al*. 1993). I adopt this argument, below, through my analysis of the politics of Aboriginal eye health in Australia.

The Politics of Aboriginal Eye Health Policies and Programs

The National Trachoma and Eye Health Program orchestrated by Dr Hollows in the 1970s was the Commonwealth government's first concerted effort to curb rates of blindness in the Australian Aboriginal population (Royal Australian College of Ophthalmologists 1980). Public health scholars argue that the National Trachoma and Eye Health Program was also one of the earliest instances in which Aboriginal health politics were brought to the fore. It raised issues such as Commonwealth versus State responsibility, Aboriginal participation, and environmental influences on Aboriginal health (Briscoe 1991; Saggers & Gray 1991).

Ophthalmologists today narrate the story of the Aboriginal eye health program with anecdotes about these early politics:

> In 1976 the National Trachoma Eye Health Program began and was federally funded. The Commonwealth government wanted to help Aboriginal health… Fred Hollows spoke with the Fraser government. There was a 'renaissance' in some way about Aboriginal health. Fred convinced the government to do something. For the College of Ophthalmologists, it was the last thing they wanted to do, but Fred bullied and bludgeoned them into thinking it was a good

> thing to do. It set up and ran for two or three years and resulted in a report that put together a health care delivery system with the Commonwealth providing the funds… The states got shitty that the funds were going from the Commonwealth to provide these services; the states wanted to be part of the action. The Commonwealth had to broker a deal that it would hand over responsibility to each individual state. Then it got lost in the state bureaucracy, which didn't have a broad perspective. Little Aboriginal semi-community-controlled organisations led to money just disappearing into the sand. *(Non-Aboriginal ophthalmologist)*

Frustrated by the complex political environment of Australian Aboriginal health, Hollows eventually took his energy and commitment overseas:

> Aboriginal health became politicised… There was a lot of political dissension or disagreement within Aboriginal communities as to what were priorities, who was controlling what, who was coming from outside and who was coming from inside… Hollows couldn't see that there was a way that he could move Aboriginal health along in a policy sense. He could still do things as an individual eye doctor—as he did in Burke—but in an hour or week's activity he could make a bigger difference in Eritrea or Nepal, which was where he was spending his time. *(Non-Aboriginal ophthalmologist)*

The torch was then taken up by the Australian ophthalmologist Dr Hugh Taylor, who had returned to Australia from The Johns Hopkins University in Maryland, USA. Like his predecessor, Taylor built his medical career around the prevention and treatment of blindness in Aboriginal communities. Government bureaucrats describe Taylor as the most important and influential person in Aboriginal eye health:

> He's played an incredibly significant role, broadly speaking, in terms of the Australian population and the international eye health world, but because he's done this eye health report with the Minister he's now identified as being the high level person in ophthalmology who's involved in services to Aboriginal and Torres Strait Islander people. *(Non-Aboriginal government bureaucrat)*

The Fred Hollows Foundation—a charitable organisation established to support ophthalmic work in Asia, Africa and the Pacific—provided a link between the work of Drs Hollows and Taylor:

> A couple of strands came together: the Fred Hollows Foundation had been working on Aboriginal eye health; Hollows started in public health and Taylor is on the board of the Foundation; the Foundation wanted to find the right angle to get into Aboriginal health. Fred Hollows had dropped out of Aboriginal health in the mid-1980s because it had become so politicised and he was so frustrated that he couldn't get anything done… He still continued to provide eye health services to the community in Burke, far south-

> western NSW, but basically wasn't doing any major activities. The Foundation was started in 1992/93. *(Koori scholar)*

In addition to Drs Hollows and Taylor, another ophthalmologist associated with the Hollows Foundation, Dr Gary Brian, was instrumental in attracting the Commonwealth government's attention to Aboriginal eye health. The Minister for Health at the time, Dr Michael Wooldridge, was also a crucial player insofar as he had demonstrated a particular interest in Aboriginal health:

> Gary Brian, with funding from various places, was funded to work for two or three years in Cairns/Thursday Island… He provided eye care for the Foundation… [He] began to nag Wooldridge for funds for Aboriginal eye health… Wooldridge was interested in Aboriginal health generally… Aboriginal health had been split off from ATSIC where it had been for the preceding half dozen years… This new office of Aboriginal health was set up and they had to look to see what they were going to do… Eye health had been an issue on and off the board in Aboriginal communities for the last twenty years, really since the trachoma program was initiated. Wooldridge had particular interest in Aboriginal health because he had spent some time working in central Australia in an Aboriginal community [Hermansberg]. Quite extraordinary to have a health minister who was not only a physician but who had also worked in Aboriginal communities. Wooldridge's main interest was in diabetes, explosion of diabetes in Aboriginal people. Out of the blue, Taylor got a call from Wooldridge to ask him to undertake the review of eye health. *(Koori scholar)*

The commencement of Taylor's eye health review coincided with the establishment of the Nganampa Health Council, a peak Aboriginal community-controlled health organisation with headquarters in Alice Springs. This period, the early 1990s, marked the historical moment when political advocates from Aboriginal organisations sought formal partnerships with government departments and health policy makers. Whereas the Commonwealth government's previous eye health strategy had been to fly ophthalmologists in and out of Aboriginal communities, the Nganampa Health Council and other Aboriginal organisations demanded to be much more integrally involved in the eye health review. Aboriginal communities no longer tolerated invasive, government-imposed health inspections:

> It's their house, it's their homes, it's their backyard. No different from suburban streets. You can't run out there and say, 'Right, get out here. We'll test you all.' It's not ethical. *(Koori eye health coordinator)*

At a fundamental level, however, the eye health review process echoed past colonial practices; the Commonwealth government issued a directive for medical specialists to design and conduct a national survey of Aboriginal eye health:

> In 1996, Michael Wooldridge, the Health Minister—being a GP—obviously thought we'd better do something, too. So he commissioned

> Hugh Taylor to do an eye health review of what is the state of eye health of Indigenous people, after the work Fred Hollows has done that dealt with trachoma… So that, if you like, really kicked it off. Hugh did an eye health assessment in Indigenous communities, which is really known as the *Taylor Report*. The recommendations out of that were translated into policy and program, which is the eye health project we have going. So that's more or less the history of it. It's only five years, I suppose. *(Koori eye health coordinator)*

The top-down nature of the policy process is illustrated by the role played by the Minister for Health's advisor:

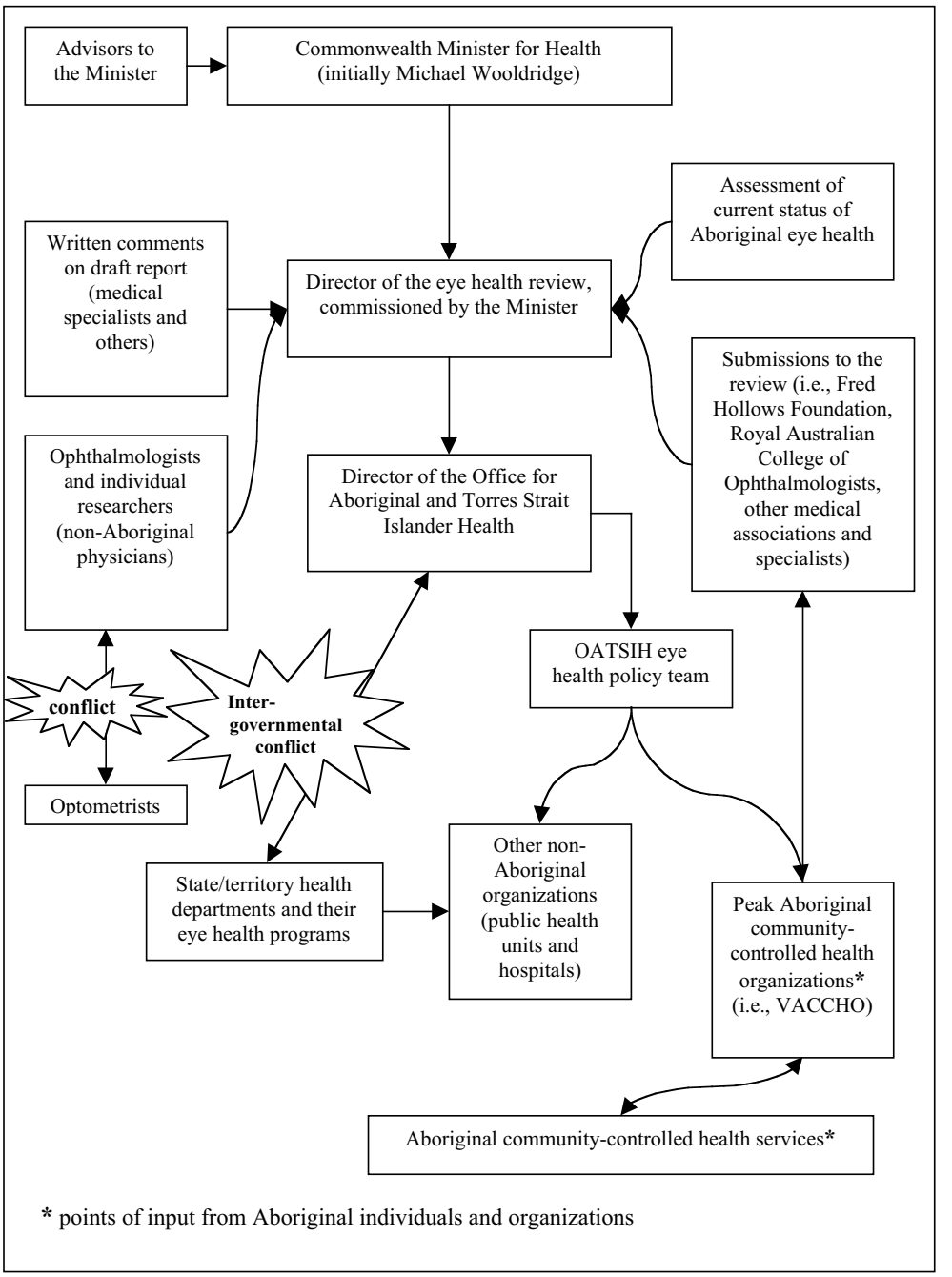
> Essentially the role of the advisor occurs at the point of framing the terms of reference for the enquiry and essentially working through a proposed methodology. Not in terms of the expert inputs, but in terms of a general framework for developing a national consultation or who the key stakeholders might be, placing the objectives of the study within the broader health policy environment. So the advisor will be aware, for example, of the linkages between the potential policy for eye health and other related policy areas like diabetes or environmental health or whatever. If an advisor sits back and does nothing, there's every chance that nothing will happen. The odds are stacked against new initiatives happening and the intransigence of the bureaucracy is such that it's a constant frustration for Ministers and their staff when they actually want to get something to happen. *(Non-Aboriginal government bureaucrat)*

If one were to sketch the hierarchy of people responsible for eye health policy, the Minister for Health and his/her advisors would occupy the top echelons. Below them would be Dr Taylor, ophthalmologists and individual researchers, various medical associations, government bureaucrats in the Office for Aboriginal and Torres Strait Islander Health, State/Territory government departments, other non-Aboriginal institutions such as public health units and hospitals, and, finally, peak Aboriginal community-controlled health organisations and eye health coordinators in Aboriginal community-controlled health services. (See Figure 1)

The complexity of the eye health network and the hierarchy of players within that network exacerbate conflicts and lead to breakdowns of every sort. Even straightforward epidemiological information about the rate of eye diseases is lost in the fray:

> There are a lot of players in this network. Sometimes you have to work through the national coordinating group, but you also have to get that information from the grass-roots because usually the national organising group don't know what the grass-roots is talking about or thinking about in a particular area… If you ask them how much trichiasis there is, everybody up and down the chain will say that there is no trichiasis and no problem… But then you get down

Figure 1: The eye health review process and policy hierarchy



> and you find that twenty per cent of the elderly are blind from trichiasis. This would probably be true of anything… In-grown toenails… It isn't eye-specific or Aboriginal community-specific. *(Non-Aboriginal ophthalmologist)*

The Commonwealth government gave Taylor approximately six months to write his report summarising problems, issues and opportunities in Aboriginal eye health. The first two months were devoted to the collection of information about the current eye health situation. A non-Aboriginal ophthalmologist, Dr Neil Thomson, was asked to assess the national status of Aboriginal eye health. Thomson used data from published reports, information from State/Territory health authorities and from Aboriginal health services, prevalence surveys, and anecdotal evidence from practitioners in the field (Taylor 1997).

The report that came out of Taylor's review, *Eye Health in Aboriginal and Torres Strait Islander Communities* (Taylor 1997), was for the most part well received by the Commonwealth government and had a positive political profile at the national level (Torzillo & Kerr 1991). Taylor outlined seventeen specific recommendations derived from the following overall themes:

- The need to develop clinical best practice guidelines for primary eye care in Aboriginal communities, and to train Aboriginal Health Workers and nurses to provide primary eye care.
- The need for all three tiers of government—Commonwealth, State/Territory and local—to share responsibility for the provision of equipment, resources, training, services and funds for eye health.
- The need for a National Information Network to improve the collection and analysis of epidemiological data on Aboriginal eye health.

The Minister for Health and the Prime Minister used the report as an opportunity to demonstrate to Australian and international audiences the government's commitment to improving Aboriginal health:

> Eye health, in theory, or at least in word, had the full endorsement of the government. Wooldridge, when the report was launched at the press conference, one of the national TV reporters said, 'What are you going to do about trachoma?' and he said, 'We'll do whatever it takes'. They said, 'What do you mean?' And he said, 'Whatever it takes'. You can't get better national TV endorsement than that. The review was presented and accepted by Parliament. The only time our Prime Minister has been in an Aboriginal community as Prime Minister, he was up in Nhulunbuy, NT [Northern Territory]. He had only one program he could announce, and that was the provision of azithromycin to Aboriginal communities… But there, again, the government stuffed up because they only approved the

> adult dose—they forgot to approve the paediatric dose—and of course half the people you're going to treat with trachoma are kids, so it took another year and a half to get that done… But then it took about another year to get it onto the register for drugs, the listing for use in Aboriginal communities. *(Non-Aboriginal ophthalmologist)*

The Commonwealth government's preoccupation with proving to a national and international arena that it can control eye disease in Aboriginal communities makes Aboriginal eye health a particularly fascinating case study of the politics of community–government relations:

> I think the difficulty with eye health, too, is its political nature and it is internationally political by nature in Australia, because of the trachoma element. And it's an unresolved issue that we don't have enough data to even really know what's out there, in some cases. But we're driven not just by local fora but also by international fora, the World Health Organization and other countries that put pressure on the Australian government. The head of state, here, has pressure on them about issues that filter down to this tiny little program that is very political. *(Non-Aboriginal government bureaucrat)*

These politics make the implementation of Taylor's recommendations a task that is easier said than done. General bureaucratic inertia and other forces work against the success of eye health programs:

> It's had the express support and endorsement of the Prime Minister, the Minister of Health, and still almost nothing's happened. That's really depressing; it makes you very despondent. I could easily say all these things haven't happened. And I could easily say all these things should happen. But, there's some twists and turns in the political structure of the states on the one hand and with the predominantly Canberra bureaucracy on the other, that I think are institutional blockages. Because it hasn't been politically attacked. It isn't as though the Aboriginal groups have campaigned against it, or that the Labor party has campaigned against it, or that the Save the Whales [group] have been out against it… There has not been any group attacking it; everybody is giving it more or less lip-service, it's just the bureaucracy and the implementation have just ground it up in little pieces and stopped anything happening. *(Non-Aboriginal ophthalmologist)*

Conflict between Commonwealth and State/Territory governments is a significant impediment to the implementation of Aboriginal eye health policy:

> In the US it took four score and seven years for the states and the federal government to sort out their responsibilities. We don't need another Gettysburg, but we've run a hundred years and we still have not sorted that out. In some ways, the biggest impediment to the health of the Australian people is the Commonwealth structure, with

> the states always playing games with the Commonwealth and the Commonwealth always playing games with the states about funding. And that's for health, generally. For white Australia, most people are sufficiently sophisticated to be able to get through that. Aboriginal people get caught in that trap. But they're doubly trapped because the Commonwealth has got specific responsibilities for Aboriginal health, and will do some things but won't do other things. In eye health, particularly, you are caught where the Commonwealth is funding the eye health workers and may be funding teams to go and look at them, but the surgery has to be done at a state facility. So they can play games and say, 'Oh, we don't have any money, we won't do it'. Or, 'we can only do one case a year, or three cases a month', and the whole thing falls apart. *(Koori government bureaucrat)*

Structures and processes within governments and professional institutions influence Aboriginal eye health programs. Commonwealth government bureaucrats use the metaphor of a 'filter' to describe the many layers through which eye health policy must pass before programs reach the ground level:

> This is just a representation of what kind of filter process the policy stuff has to go through, or decision-making has to go through, to actually get to the ground and be implemented. So we're looking at a national level, there's the planning fora, there's the health council, there's our advisory group that we set up. At the state and territory level, there's the state and territory affiliates that are part of the state and territory-based [*Framework*] *Agreement* fora, there's regional reference groups or state and territory-based reference groups, there's Aboriginal community-controlled boards, there's ATSIC [Aboriginal and Torres Strait Islander Commission] representatives and they're part of the *Agreement* fora so they input through that… There's vision impairment prevention program committees… There's regional reference groups at a state and territory level. The complexities that we work with are not often conceptualised in a total way. I think that a lot of what we talk about can be tracked back to a complexity that has just never been looked at. I think we sound very critical of most things. I think we're trying to get across to you a sense of what the difficulties and challenges are of trying to implement a program like this. *(Non-Aboriginal government bureaucrat)*

As in other areas of Aboriginal health, Aboriginal eye health policy is plagued by high rates of turn-over within government bureaucracies. High Taylor describes this phenomenon using the metaphor of George Washington's axe: with seventeen new handles and three new heads, the structure of the bureaucratic system rarely changes but its composition bears no resemblance to its predecessors. Almost as soon as Taylor's report was presented to the Commonwealth government, for example, the

director of the Office for Aboriginal and Torres Strait Islander Health left to be replaced by a new director. Within a four-year period more than a dozen people have been responsible for Aboriginal eye health in that one office:

> It is just ridiculous: no commitment, no understanding, no institutional memory… Very little progress. *(Non-Aboriginal government bureaucrat)*

In addition to institutional constraints, economic constraints also affect the outcomes of all public health programs. The Aboriginal eye health program is no exception:

> Once you offer something up to the Prime Minister, he—this was my experience—inevitably there was never enough money… The way that budgets work is that they are not a bottomless pit; they are finite. So to try to advance on a recommendation outside of the normal budget process is quite difficult. I forget the value of the program he announced, but basically the advisors were all asked to try and find, in nooks and crannies, under-spent or whatever, or by re-phasing forward commitments through programs, to try and get the money to satisfy his need to be able to fund an announcement. But anyhow, he did ultimately make that announcement and Hugh [Taylor] will probably say that nothing ever happened as a result of it. God only knows if the money was ever spent; I'm assuming it was. *(Non-Aboriginal government bureaucrat)*

Conflicts between professional associations are another problem. While optometrists receive Commonwealth government assistance through a Visiting Optometrist Scheme in order to service Aboriginal communities (OATSIH & OAA 2000), ophthalmologists do not have an equivalent scheme. This precipitates professional turf wars between ophthalmologists and optometrists:

> And then you get into the whole ophthalmologist versus optometrist, that whole cross-profession debate within eye health areas. So there's a cross-cutting of politics, not only community–government-service deliverers but also in the specialist area as well, which gives it, I think, a lot of complexities. *(Koori scholar)*

> I think this is a global thing among specialists: you have ophthalmologists and optometrists and never the twain shall meet, in most cases…. There's a hierarchical thing here because ophthalmologists are medical specialists, optometrists are optometrists, they're not trained through specialties… They're four-year degrees. The other one's a ten-year degree. *(Non-Aboriginal ophthalmologist)*

> It is very hard to align because you get one group on board to help out and the other group of specialists doesn't want to come on board because they don't want to work with them. There's a whole lot of dynamics there that I don't think we know. We just try to coordinate

> around that and hope that we can get the best access for the communities because that's ultimately what the program's about. Cutting through those politics. *(Koori scholar)*

The government's lack of epidemiological, social, economic and other information about the Australian Aboriginal population exacerbates health inequalities. Without knowledge about barriers to, and gaps in, eye care in Aboriginal communities it is difficult to design and implement effective Aboriginal eye health policy and programs:

> This very senior Koori person, not just in health, he said: 'Why don't Koori kids wear glasses?' And I said, 'We don't know. We don't know if they don't need them, so they don't wear them. We don't know if they do need them and don't want to wear them. Or, do need them, do want them, but can't afford them.' There's a whole lot of things like that where we haven't got to the issues. Investigating those health issues. Understanding those. I think we've got to do a lot more of that. *(Non-Aboriginal government bureaucrat)*

Finally, ideological schisms are yet another source of tension in Aboriginal eye health policy processes: non-Aboriginal government bureaucrats argue that the politics of Aboriginal eye health today are not as overtly patronising as they were in earlier decades.[4] The list of organisations and individuals contacted as part of Taylor's eye health review includes more than 100 Aboriginal community-controlled health services. Non-Aboriginal government bureaucrats in OATSIH contend that the eye health policy process has been driven by 'Indigenous input':

> From our perspective, the way that we did get a lot of the Indigenous input was, first of all, the Minister commissioned someone who was espousing himself as being very, very strongly connected to Indigenous people on the ground. So, from the start, there was the person who actually conducted the review. The system or the Commonwealth claims that he had a very… Now, I'm not saying whether it was or not, I'm just saying that's what was put forward. Then Gary Brian who is the ophthalmologist from far north Queensland was brought in. He did a lot of work with Fred Hollows in Aboriginal communities. He was brought in to engage with the Aboriginal communities on the ground. Then, once the implementation plans were done, they were then put in to whatever regional reference group was developed by the state and territory office of the time. So we've got, in Queensland, very strong regional reference groups that are functioning. In South Australia, I understand that it's more based on a local agreement type of model, rather than regional reference groups. In WA [Western Australia], there's a very strong state-wide reference steering committee, so the reference committee has the powers of decision-making. So, from

4 The Queensland government, for example, suspended the National Trachoma and Eye Health Program in 1977 because two Aboriginal field officers with the program were known to be political activists (Osborne 1982).

> our perspective at a national level, we developed an Aboriginal and Torres Strait Islander eye health program advisory group that incorporated community-controlled health organisation representation, coordinators, but also included specialty area groups and that sort of stuff as well. I guess I feel that our aim is ensure that, at the end of this program, it is being developed and run and monitored and everything by the Aboriginal-controlled health sector and is being supported through administration by the Commonwealth and state and territory governments... So what we've tried to do is to set up national mechanisms to allow that to happen. *(Non-Aboriginal government bureaucrat)*

From the perspectives of people in Aboriginal communities, however, the Aboriginal eye health policy process lacks Aboriginal leadership and participation. Aboriginal political advocates pay close attention to the genesis and ownership of programs. They contend that the Aboriginal eye health program was initiated by government bureaucrats and health professionals and is essentially 'owned' by non-Aboriginal people. Although Aboriginal political advocates did not campaign against Taylor's eye health review and recommendations, neither were they integrally involved in the policy process:

> The eye health program is in some places referred to as the Hugh Taylor program… That 'top-down' versus 'bottom-up' is very clear. *(Koori eye health coordinator)*

The Aboriginal eye health policy process contrasts with other policy processes that were led by Aboriginal communities. In a discussion about the importance of Aboriginal community control, one senior bureaucrat in OATSIH cited the National Indigenous Australians' Sexual Health Policy process (ANCARD Working Party on Indigenous Australians' Sexual Health 1997) as an instance in which Aboriginal people were involved in everything—from public health research to program design, implementation and evaluation:

> We called together a conference in Central Australia… People felt that there was a great need to go back and canvas with communities. It was around HIV, but it was about the broader issue of STDs. [It was] very important to go back and canvas with communities [about] what their perceptions were, what their issues were... It had an extensive consultation across the country. It was about a two-year process. It then ended up with a report that everybody had ownership of, that was then endorsed by government and then went through to implementation. Which was a different approach to eye health… And I think it's important to have a look at that, to look at the ownership and the implementation process. *(Non-Aboriginal government bureaucrat)*

Aboriginal researchers, representatives of Aboriginal community-controlled health services and organisations, and Aboriginal bureaucrats reiterate in discussions about

eye health policy that public health programs are most successful when they are initiated and managed by Aboriginal communities. That entails the involvement of Elders, Health Workers and other community members both in decision-making processes and throughout all stages of public health programs:

> I believe the Elders have to be there. And obviously the Health Workers. But, yes, unless you've got the Elders involved so that the community's going to be committed to something… And sometimes some of the Health Workers are Elders, as well. That happens, too. That's very good. *(ACCHS executive officer)*

The boards of directors and managers of Aboriginal community-controlled health services also have to be fully immersed in the policy process. This is because only they are privy to knowledge about their organisations' priorities and the capacity of their organisations to implement specific programs.

Is eye health a priority in Aboriginal communities? According to many Koori community members, there are more pressing concerns than one's vision:

> Right, my son just committed suicide. Why do I give a shit whether he could see or not? *(Koori political advocate)*

> I don't think eyes was one of the key priorities at all. That was one of the main hiccoughs. And you try to tell the eye health professionals that it's not a priority for them. And they go, 'But blindness should be a priority… rah rah rah…' And then you'd say, 'Yeah, but most of them die before they get blind. So they can't see; it's a part of aging.' Diabetes was more of a priority. So what [we] were trying to tell people, and the co-ops themselves, is we really have to organise it as a diabetes clinic. So it is a whole; we're looking at not just their eyes, but their feet, their liver, you know, getting specialists to them and stuff like that. *(Koori eye health coordinator)*

Non-Aboriginal bureaucrats acknowledge that the Commonwealth government's lack of concern with Aboriginal communities' health priorities is patronising:

> There's a bit of paternalism there, whether we like it or not. Because we're the ones saying, 'We think you're going to always have to look after your eyes. Even if they're screaming and saying they're dying.' *(Non-Aboriginal government bureaucrat)*

National Outcomes of Aboriginal Eye Health Programs

In October 2001, I travelled to Canberra to speak with government bureaucrats in the Office for Aboriginal and Torres Strait Islander Health about how Aboriginal eye health programs are implemented across Australia. One person on the team was a newcomer to Aboriginal eye health, while others had been involved in the National Aboriginal and Torres Strait Islander Eye Health Program over longer periods of time. Fascinatingly, whereas the newcomer wanted to discuss the program's epidemiological

goals and outcomes, the people who had worked on the program since its inception steered the conversation to a discussion of the general politics of Aboriginal eye health policies and programs.

The OATSIH eye health team in Canberra is not privy to internal community politics. Aboriginal eye health coordinators sporadically convey messages back to Canberra about what is happening in their communities. These messages indicate that inter- and intra-community politics significantly influence their ability to run eye health programs. Rivalry between communities, for example, drives some to refuse to run a program that has been adopted in neighbouring communities:

> Even just down to 'because you're in another group and you've done it, I don't want to know about it'. There's such politics. You'd be aware of the politics, no doubt, having talked to certain people. The politics are such that in some cases we have no strategy to know how to actually progress things while respecting the process of politics that are happening at a local or regional level. *(Non-Aboriginal government bureaucrat)*

When I met with the OATSIH eye health team in Canberra, the Commonwealth government was in the planning stages of an evaluation of the National Aboriginal and Torres Strait Islander Eye Health Program.[5] Up to that point, OATSIH's ability to assess the outcome of programs was limited to anecdotal evidence and scattered reports from State/Territory consultations. The eye health team senses that outcomes of the program vary considerably across the country:

> What we don't know is the extent that the plan has been rolled out. We know it varies from state to state, sometimes for historical reasons. *(Non-Aboriginal government bureaucrat)*

> You can see how differently the program is running in different states already because, on the one hand, you've got a small state that doesn't seem to be getting specialist access, as such, out to communities. Whereas in other states and territories such as South Australia, for instance, they fly out with the RFDS [Royal Flying Doctor Service] or they charter planes and they go out to communities. Because [there are] a lot of inequities in Indigenous health in this country… One of the fundamental ones in terms of specialist services is that you just can't get specialists out to remote or even rural areas. The eye health program has tried to collaborate with specialists and some of the training organisations to try to get more specialists out there. *(Non-Aboriginal government bureaucrat)*

Every Aboriginal health service's support for eye health programs is influenced by infrastructural, workforce, economic and other factors, including local Aboriginal people's beliefs and practices. Reflecting upon barriers encountered in the imple-

5 OATSIH was expected to publish that national evaluation in 2003. NACCHO, State/Territory governments, eye health program coordinators, ophthalmologists, optometrists, and others comprise the reference group that is conducting the review (Comm. Dept of Health and Ageing 2003b).

mentation of Aboriginal eye health programs, the OATSIH eye health team is aware of the need for Aboriginal communities to shape the way that eye health programs are implemented at the local level:

> Success of a project is very dependent on regional locality of a program, anyway. As you've probably found out, the Aboriginal community is very different from one end of the country to another. And so, what works in one place may not work in another. *(Non-Aboriginal government bureaucrat)*

> There were some cultural aspects. Like at the Top End [Northern Territory] they didn't want the photos taken of the back of their eyes because it was a cultural thing… So what we did was ask the Health Workers, 'Who should we see?' They were the ones that would round them up for us and let them know. We'd tell them a couple of months in advance, 'We will be visiting your service at this time. Can you have your patients all ready for us?' and stuff like that. They'd do all the work on the ground. *(Non-Aboriginal government bureaucrat)*

Some problems with Aboriginal eye health programs are experienced Australia-wide. The OATSIH team laments, for example, that across the country it is difficult to recruit, train and retain Aboriginal eye health coordinators. Indeed, some eye health coordinators are clearly inadequately informed, let alone properly trained, to carry out their role:

> The fact is that these people don't even realise that they are what we've called eye health coordinators since 1998… I went down [to Adelaide] for a meeting with all the coordinators from the state of South Australia and I was sitting there with a very large group of people—South Australia is a very large region, so you have people who are from up here, Maralinga way, which is right up near the Northern Territory, and then you have people from down at Ceduna, which is near the coastal areas, Nullarbor Plain way—and so I was sitting at this meeting and I was talking about the eye health coordinator position and what it does, and one of the fellas said, 'Hey, when are you sending these coordinators out to us?'. And I was sitting there thinking, 'That's an interesting concept, as you are coordinators'. I sat there for a half hour thinking: How am I going to tell these guys that they actually are coordinators? I did in the end say, 'Look, you are coordinators. You get funded for that position.' But their CEOs, the health services that they worked for weren't telling them that that's what their positions were. *(Non-Aboriginal government bureaucrat)*

Problems are also encountered across Australia with respect to incentives for ophthalmologists and optometrists to work in Aboriginal communities. Even when there are eye specialists in close proximity to Aboriginal community-controlled health

services, they often express a preference to work in hospitals and mainstream settings:

> Another problem that arises with some specialists going out in the rural areas—not remote, so much, but in rural areas where there's already a hospital there that they work out of—is that some of the specialists refuse to go down to the community-controlled health service itself. And so, the Aboriginal people won't come up to the hospitals because they want to use their own service but the specialists refuse to use that service because they want to keep using the hospital that they like to use. Then that's problematic because it means that Indigenous people are still missing out in some areas, despite the fact that there's a specialist that comes there. *(Non-Aboriginal government bureaucrat)*

In an attempt to improve Aboriginal people's access to ophthalmologists, the Commonwealth government introduced a Medical Specialist Outreach Assistance Program or MSOAP (Comm. Dept of Health and Ageing 2003):

> It's not just about eyes; it's about all medical specialists and how do you encourage them to get out of the cities and go into the bush? The idea was that you pay them money for their travel, pay them special slush funds to organise training sessions for local GPs, a big amount of money for a tiny little meeting. It was quite flexible and loose, just to find ways of doing more… They can go out and bulk-bill, but that wasn't enough because of the costs involved in getting there. So this program was to cover their costs so that when they got out there they can bulk-bill and make money. *(Non-Aboriginal government bureaucrat)*

> There has been people saying they need to be paid $2000 a day and that's the preferred arrangement: You pay $2000 a day and if they just drink coffee all day because everybody's off at a funeral they'll still get $2000 to offset the fortune they could make in the city. They're still doing it as a goodwill gesture, but they didn't want to lose as much… When you go to an Aboriginal community, no matter how well prepared and planned you are, on the very day you get there you can ring up and say, 'Everything okay?' and you still get there and you can't work. It happens and they know it. There are people that are really likely to lose a lot of money out of it. When a public servant goes out there, he'll get paid anyway, even if they're not there. But a specialist, it was a bit of a hard call to say, 'Go out there. If they're not there, bad luck.' So one of the things we did with [MSOAP] was we said, 'We'll give you $600 as a bottom line, even if no one's there, or the difference between what you make on [Medicare] and that'. That was the trial. But even with $600, they're doing it for love not for money, obviously. That remains an ongoing issue and it may remain an issue for future exploration after the

> review, as to whether we are being realistic in our payment arrangements. The trial was to find out if it actually works. *(Non-Aboriginal government bureaucrat)*

Financial incentives such as MSOAP are designed to improve the delivery of health care in remote Aboriginal communities. While these strategies may be effective in central, western or northern Australia, they are not suited to urban and rural Victoria:

> The one problem we have—and I imagine, again, it is a bit like the United States—is, when you have a national program, you've got really diverse geography and you've got really diverse populations. You can't make one size fit all. It's like saying, 'You're from Connecticut. So what we do in Connecticut we can apply to New Mexico... What's the problem?' The problem is that one is on the east coast and it's on the bloody ocean, and the other is in the middle of the bloody desert in the south-west. They are not going to be exactly the same. That's the problem we have here: that sometimes policies are put forward that might be applicable to northern Australia [but] they just don't work here. We have to modify them. And that was the problem with the eye health program: it was formulated around the concept of isolated communities, of needing to take specialists out to the back of beyond. That's fine. That works well out there and so it should. It deals with their particular needs. The problem is, Victoria is a highly urbanised environment where nobody is remote from anywhere. So, therefore, while it might be attractive to say to an ophthalmologist, 'Come with me and we will fly you out to the middle of the desert and we'll help you with the tribal people, we'll get right into it', trying to say to somebody, 'Come with me to Bendigo…' what you get is, 'Piss off'. So that part of it was different down here. We didn't need to take people out. What we needed was to get them access to the existing services. You don't have optometrists in the middle of the Tanami Desert. In fact, you have nothing in the middle of the Tanami Desert except remote Aboriginal communities. In Victoria, optometrists are a dime a dozen in every bloody little population of over a thousand people in the state. There's bound to be an optometrist. There's one in the town I grew up in, in Yarrawonga, that's about three thousand people. There was an optometrist there. And if you wanted to go to the big optometrist, you went to Wangaratta. So our issues with dealing with it were different than to how the Commonwealth policy and program were generally formalised. And that's made it a bit difficult, here, to try to implement it. *(Koori government bureaucrat)*

I turn, now, to an analysis of the Victorian Aboriginal Eye Health Program to examine what has and has not worked in Koori communities.

Victorian Aboriginal Eye Health

The earliest work in Aboriginal eye health in the State of Victoria began with a program offered through Rumbalara Aboriginal Co-operative, a community-controlled health service outside the town of Mooroopna, three hours north of Melbourne. Local Kooris and non-Aboriginal consultants were involved in the development of the program. A social scientist, who was a consultant for Rumbalara, reminisces about this particular eye health program:

> I was involved in doing a low-vision kit that was published by the WHO. Looking at very simple forms of assessing vision. Some people here heard about that and thought, 'Oh, that might be useful'. It was then the Association for the Blind, now called Vision Australia Foundation, up in the Goulburn Valley, said, 'There's Koori people in our community but they're not utilising the service. But if they did, we're not quite sure what to do.' So they said would I come up and get involved with them in the community. I said, no I wouldn't; the invitation had to come from the community. In a couple of weeks, that came. So then that was Rumbalara in the Mooroopna, Shepparton area. I was extremely lucky because the [Chair and CEO of the co-op] invited Elders [to the first meeting]. So it was great just to be able to talk to people. That was first contact. And I was absolutely raw and new to the whole thing and had not worked with Koori people before. *(Non-Aboriginal consultant)*

The eye health program run by Rumbalara was a collaborative initiative between Aboriginal community-controlled and mainstream organisations. Rumbalara was, therefore, able to tap into resources that otherwise would not have been available to it. Significantly, the program not only provided eye care to the community, it also increased Rumbalara's capacity to conduct its own research:

> We worked together on putting together a funding proposal, first to the NH&MRC [National Health and Medical Research Council]. We were short-listed for that, which was interesting. It didn't get it, so we then put together a consortium of foundations. For Rumbalara, that was the first time they'd had private or foundation funding. But besides looking at eye care, we broadened it… Which was to say, 'Look, we don't know what the issues are. We need to find out what they are.' But obviously one of them was diabetes and diabetic retinopathy. So it was getting screening for diabetic retinopathy happening within the medical centre. It was training a Health Worker to do that. But we had a research component of that. And rather than just me doing the research, it was training the Health Worker in research. That was a very interesting development and relationship. And at some stage in the process, [the CEO of Rumbalara] said, 'I can see what research is about, what it does'. Just some very simple

> things in planning the next stage: 'Gee, I've got a problem'. Looking at the data that we had, analysing that, and it showed what the next stages were, what the issues were, and suggested some possible ways… So that was really very good. *(Non-Aboriginal consultant)*

Thinking about Aboriginal eye health programs in Victoria, people describe Rumbalara's eye health program as a best practice model for the State. Other Aboriginal health services, the Victorian Aboriginal Community-Controlled Health Organisation, and various peak Aboriginal organisations outside of Victoria have noted the success of Rumbalara's program:

> There was a report for that. You can have a look at that. It's called the Rumbalara Eye Care Project. That's actually at VACCHO, too, somewhere. And they received funding to do a two-year study in a community. That was to employ a project officer that was based at the local level in Rumbalara, to see what the actual eye conditions were amongst Koori people. They did extensive data on that. They had over a thousand clients. *(Non-Aboriginal government bureaucrat)*

> The work at Rumbalara pre-dated the Koori eye care project. It was probably, if not the impetus, certainly the fact that people could see that it worked, that Health Workers could be very effective in vision screening, in screening for diabetic retinopathy. [It] was then taken up in other communities. During the project, [the CEO of Rumbalara] and I met with VACCHO, the VACCHO members when they had members' meetings. And we talked about the program. And lots of people made contact from other states, as well. So even though the screening didn't keep happening the same way in Rumbalara, it was certainly an impetus or a model that people could see was happening. Particularly the role of Health Workers and the role of the camera, and the vision screening that we did in schools with children and in the medical centre. So, it was probably a pretty good outcome. *(Non-Aboriginal consultant)*

With the success of Rumbalara's pilot project, VACCHO received funds from the Victorian government in 1988 to conduct a State-wide study of eye health:

> We were funded in 1988 at the Eye and Ear Hospital, from the Department of Human Services, to conduct a study state-wide, to further implement the project that was happening at Rumbalara, [and] to see what the actual eye conditions were all over the place. Because there was a high incidence of diabetes in Rumbalara, but there wasn't a lot of blindness or stuff like that. I suppose because of the death rate, I reckon; more people would die earlier, so the prevalence of them being blind from retinopathy was a less risk. *(Koori eye health coordinator)*

VACCHO eye health project officers recall that their challenge in the early phase of the State-wide program was to convince Koori communities that eye health should be a

public health priority. They also had to gain the trust of local Aboriginal community-controlled health services and Health Workers:

> I was based at the [Melbourne] Eye and Ear Hospital in partnership with VACCHO. [We were] to go all over the state to introduce the eye health program. That was mainly, we had one camera, one retinopathy camera, a blood analyser, and we just went around the state and just told them, 'Here's this equipment. It's to check your eyes and stuff like that…' We only [saw] seventy-two people that year. It took a year to get the confidence of the community to actually come in. Because I'm from Melbourne and when I go to the community I'd have to say where I'm from, who my family was, stuff like that, even before I see the patient. And building up that network with the actual Health Workers. *(VACCHO eye health program officer)*

Then, following Taylor's national review of eye health in 1997, the Commonwealth government provided the funds for the Victoria-wide Aboriginal eye health program:

> Part of that funding was to actually get twenty-six eye Health Workers on board, through the training, through the hospital. So we got funding through OATSIH to do a two-day training course, state-wide, here in Melbourne. And we ended up getting fifty. So the participation rate was really good. And we did it through the [Eye and Ear] Hospital so that they would be able to form stronger links with the Eye and Ear… They were Health Workers from across the state. Two from each service, it ended up being… Then, from that, we got additional funding from OATSIH and the program was then transferred over to VACCHO. And in that funding we were given money to do cross-cultural awareness training, and still deliver training to the Health Workers and continue with our screening of patients. *(VACCHO eye health program officer)*

Delays in getting the funds for Aboriginal eye health from the Commonwealth led Hugh Taylor to arrange for the Aboriginal eye health program in Victoria to initially operate through the Centre for Eye Research, Australia (CERA) rather than VACCHO:

> It seemed to me, there was going to be a while until OATSIH got things up and running. So, through another source, we got some funds from the [government] health department to hire a Health Worker to do some work here, to get something set up. We employed [a Koori woman], who worked as a CERA employee for about the first 15 months or something while VACCHO put together a submission for funding... That took longer to come through than it should have but eventually some funding was there. So, for the first year, year and a half, the Aboriginal program was actually run out of this office with an Aboriginal advisory board and Aboriginal staff and we had a training course with 35 or 40 Health Workers from across

> the state here. We were acting as a *de facto* VACCHO until the funding came through. We brought in the optometrists and the [Royal Australian] College [of Ophthalmologists] and the state and Commonwealth came along to those coordinating meetings, as well as VACCHO. It seemed to be going quite well. *(Non-Aboriginal ophthalmologist)*

More than a year into the program, VACCHO entered into partnership with Hugh Taylor to develop further the Aboriginal eye health program in Victoria: Taylor brought expertise and resources to the relationship, while VACCHO brought invaluable links to Koori communities. In that sense, the partnership was mutually beneficial. In retrospect, however, VACCHO executive and board members assert that, as a community-controlled organisation, they were too swayed by the authority of outsiders:

> I remember that the findings in that [Eye Health Review] report identified a need in Aboriginal communities. That gave Aboriginal communities the evidence they needed to go and seek dollars. So they probably were thankful for that and grateful for that, because it is an area where there's no Aboriginal expertise, or at the time there was no Aboriginal expertise. So it gave us the evidence we needed to pursue funding of a program in Victoria. What happened next was that a committee was established to oversee the program and its development and implementation in Victoria. That program was based, in partnership with VACCHO—and VACCHO was probably a bit naïve at the time and continues to be on other issues, I suppose, because we hadn't had that involvement; there was no history in the eye health arena, none of that exposure in the past—so they accepted a partnership between the hospital and VACCHO. And the program was based at the hospital, which gave the hospital full control. Until we were just lucky, we got a very proactive project officer in that position. [She has] been working in Aboriginal health all her life and it was she that said, 'This has got to come out of the hospital and go to a community organisation'. And that's how it landed at VACCHO. That's my understanding. *(VACCHO representative)*

Victoria's Aboriginal eye health program was more centralised than the programs in other States/Territories. Part of the focus of the program in Victoria was on improving mainstream services for Aboriginal clientele. To that end, Koori liaison officers were hired to work in mainstream eye clinics, and cultural awareness training was provided for non-Aboriginal health professionals. Hugh Taylor's workplace, the Royal Victorian Eye and Ear Hospital, was chosen as a central site for the provision of eye care to Kooris:

> [In Victoria] there was a number of years of service delivery of a Koori eye health program being done from the Royal Victorian Eye and Ear Hospital. So I think, in some ways, what they tried to do was they had a centralised model that was different to the rest of the states and territories. The whole purpose of the program was about regionalising service delivery. But the assessment was made at the

> time of developing the implementation plan that the nature of the geography and the demographics of Victoria meant that they could centralise the model and focus on training. *(Non-Aboriginal eye health consultant)*
>
> We had the Royal College of Ophthalmology. We had the Victorian College of Optometry. We had the Optometry Association. We had the Centre for Eye Research [CERA]. We had the Eye and Ear Hospital on board… Through them, what we hoped to do was to actually get Health Workers working in the hospital structure itself. *(Non-Aboriginal eye health consultant)*
>
> Bringing people in, taking Aboriginal Health Workers through the hospitals, showing them who we were… I think the best way to do that of all is with the Aboriginal liaison officer, which was the model we pushed very hard *(Non-Aboriginal ophthalmologist)*
>
> Working with VACCHO, we've got the nursing staff sensitised, we've had some cultural awareness stuff done here, we've had the hospital sitting on the advisory committee… Hopefully there are some of those linkages that we've established that are still working. *(Non-Aboriginal ophthalmologist)*

Another component of the eye health program in Victoria was to train Health Workers in Aboriginal community-controlled health services to act as eye health workers. The target was for two Health Workers in each ACCHS to be knowledgeable about eye health so that they could run community clinics in which they would screen patients for diabetic retinopathy. VACCHO hoped that the Health Workers would be able to coordinate the movement of the necessary equipment between the communities. However, instead of running or coordinating local programs, the Koori Health Workers continued to rely upon VACCHO to facilitate eye health clinics for them in their communities:

> Some communities are very small. Some communities were very happy to have Health Workers trained to take on a role similar to Rumbalara, but many didn't want to; they were happy to have the coordinator come in and do it. So, at that stage, there was lots of discussion about VACCHO being a service provider rather than the communities being the providers of services. There was lots of difficulties or discussion about whose role it was to do particular parts of it. Whilst many of them were keen to say, 'Yes, it's fine, we'll do it', when it actually came to doing it, even though they had all participated in the initial training to do that, it didn't always happen. They'd say, 'Look, you come and do it'. So whilst that was the idea and that was how it was planned—the coordinators weren't going to be the ones doing the screening, but they would facilitate the program happening within communities—but in most communities that was not how it actually happened. *(VACCHO eye health project officer)*

> The Health Workers were busy and committed on other things. To be able to either stop doing those or to say, 'We're going to do the eye care', that was an investment in time, organising it, familiarisation with the equipment, and then actually doing it. I think for many of them, there were lots of other programs happening and there might have been other immediate or other shorter or longer term priorities. So they became the service providers which, as I say, wasn't the plan. *(Non-Aboriginal government bureaucrat)*

In the first year that VACCHO ran its eye health program, the eye health project officers were only able to see seventy-nine people across the State: eye health was not a priority for most communities. In a stroke of brilliance, the following year the eye health program officers teamed up with the Well Person's Health Check, one of VACCHO's other programs.

The Well Person's Health Check is a community-based health assessment program that travels from community to community across Victoria, and is run by the sexual health team at VACCHO (Melbourne Sexual Health Centre & VACCHO 2003). VACCHO works with the local Aboriginal community-controlled health services to organise a two- or three-day drop-in clinic at which Koori youth and adults are surveyed about their smoking and drinking habits, have their hearing and blood-pressure tested and are weighed. Women are offered reproductive advice and given the option to have a cervical exam, and both men and women are asked to provide urine samples to screen for sexually transmitted infections. Nurses and doctors from Melbourne accompany VACCHO to each of the communities, where VACCHO distributes fliers about sexually transmitted diseases (STDs) and gives out 'show bags'. Sometimes the health services provide food to attract the local population into the clinic. Most of the data from the Well Person's Health Check is collected anonymously to protect the identities of the participants, with the exception of the lab. results from the physical examinations which are coded so that general practitioners at the community-controlled health services can follow up with patients. The basic health and lifestyle information is entered into a database at VACCHO and analysed by university-based health researchers who have signed a contract to ensure that community control is maintained by VACCHO.

The Well Person's Health Check is heralded by the Aboriginal community-controlled health sector, and by health researchers nationally and internationally, as a successful program:

> What's made it a success? I've never really sat down and thought about it. Well, we're not going into a community and setting up a program that we want to implement… We did a lot of groundwork prior to implementing the Well Person's Health Check… It wasn't just someone from Melbourne—whether you're black, white or brindle, by the way—coming in and wanting to get some stats or something; it was a meaningful health program. And I know for a fact that communities out there, community people on the ground,

> are basically saying that to have a holistic health check… It wasn't all that holistic—it was holistic, but you know what I'm trying to say—where you can go to a doctor and you're not even sick… just go to a doctor, have your blood pressure taken, diabetes check if you've got diabetes, eyes checked, I don't know about sexual health… lifestyle, BMI (body mass index), all of that checked in one hit! You can't get that out there. That doesn't happen in a general practice. It doesn't even happen in an Aboriginal health service. So when communities realised what it was all about… They were a bit iffy about the sexual health, but anyways… (*VACCHO representative)*

Again, Koori community ownership and control of the Well Person's Health Check were instrumental to its success:

> I think [an] ingredient to what makes a successful program is community control. Simply because, I mean, sexual health is a sensitive health issue, okay? And I had misgivings about our community people fronting up to have that done. I thought, 'Oh god, they won't want to do it'. But given that it was… If it was a mainstream organisation they wouldn't have had a leg in. Not because of me, but because as a part of the sexual health team we knew people within the community and they saw us there and they thought, 'This must be okay'. So in my opinion, the success of delivering anything—whether it be a health program, a heritage program, whatever—is that we own the process, we control the process. And VACCHO being a state-wide peak body, we make sure that it is locally owned, also. So that is one important ingredient, in my opinion, of a health program being implemented, that the community actually develop it and run it. *(VACCHO sexual health officer)*

For two years the VACCHO eye health project officers accompanied the Well Person's Health Check offering basic vision testing and screening for diabetic retinopathy. During that period, they were able to see 1700 people. It was considered a time-saving and relatively cost-effective model for community outreach. In the long run, however, the Well Person's Health Check is not a model for primary eye care in Aboriginal communities; the Health Check only visits each community once, whereas the Aboriginal eye health program is supposed to run continuously in communities.[6]

The eye health project officers at VACCHO comment that their program was not sustainable because community-controlled health services did not assume responsibility for eye health. Ultimately, VACCHO's role was too 'hands on':

> Victoria was the only state that was actually delivering the service. Most of the other services around Australia were coordinating them but they weren't actually doing any hands-on stuff… But because [Health Workers in] the twenty-six [Aboriginal community-controlled

6 Furthermore, funding for the Well Person's Health Check was short term and had ceased by the end of 2003.

> health] services already had jobs to do, it was really, really hard for them to actually continue with doing their job and, plus, do the screening. That was one of the barriers that we still haven't combated with OATSIH to date. *(VACCHO eye health program officer)*

In an attempt to decrease its role in eye health care delivery, VACCHO encouraged communities to create regional eye care networks. Unfortunately, these networks proved to be difficult to implement; high rates of workforce turn-over—most of the trained eye health coordinators eventually quit their jobs—left health services without skills and connections to the eye health network:

> We then decided that it was much easier to do regional training so that we could get the health services all over the regions to network and start working together. That way, if the camera was in Mildura and needed to go out to Robinvale, we'd be able to form a link so that they would transport it for us. But that didn't always happen. If that did go ahead, we had problems with the camera being damaged, it wasn't packed properly, and stuff like that. And also there was a high turn-over rate: Health Workers that were trained to actually deliver the service had left, so we didn't have anyone on board to actually go through with it. *(VACCHO eye health program officer)*

> You can get the skills in a day, but it's remembering those skills. So by the time you take the camera back there it's been six months, they've forgotten, and so you have to do it again. And they've got other things happening during that time. That's why we became the service people. *(VACCHO eye health program officer)*

> We ended up with ten. Ten Health Workers because the rest had moved on. And now I think you've probably got six. Six that I know of. *(VACCHO eye health program officer)*

VACCHO's budget was stretched to the limit because its eye health officers were forced to travel across the State with the eye health program. Much to VACCHO and Hugh Taylor's disappointment, the program eventually met its demise:

> VACCHO went on and employed a third person because there was quite a lot of work, quite a lot of activity… They had cameras going around doing the diabetic screening. The problem is, the screening was not sustainable and the recommendation for a Medicare item number for the non-mydriatic retinal cameras has never been implemented, so every photo they took cost them money… The more people they saw, the quicker the money ran out. I have yelled and screamed and kicked and jumped up and down in multiple fora to try to get some sustainable funding for the non-mydriatic retinal photography… I am on the diabetic retinopathy sub-committee of the Australian Diabetes Society that has put in a submission to government to say that. I have harassed the Health Department and the Minister. People are just not going to do that. *(Non-Aboriginal ophthalmologist)*

> In VACCHO, they spent more money than they had. They had to let off staff. They had [one coordinator] working a half a day a week—that was all that was left—and even he had to… he is gone… The screening basically ran out of money. *(Non-Aboriginal government bureaucrat)*

The VACCHO eye health project officers were extremely committed to providing services to the communities across Victoria. As Koori community members themselves, their work accompanied them home. It is to their credit that they kept up their energy and enthusiasm right to the end of the program:

> In relation to the training problem, I know that the last person that was working there as a coordinator at VACCHO said that the demands were on him to do a lot of the work, which was never what the original intention was. He'd go to a place and they'd say, 'No, that's your job'. And then they'd ask him to drive down the road to somewhere else. So he was travelling all over the place, spending a lot of time on the road, moving that equipment around—and it got broken, I think, once—but it appeared that people started to get the view that he was the eye person… He was the steady one. He was the one who was always there. *(Non-Aboriginal government bureaucrat)*

Overcoming Endemic Short-Sightedness

The Aboriginal eye health program in Victoria ended just prior to my arrival in Australia. With a deficit eye health budget, the VACCHO coordinators exhausted, and only a handful of remaining community-based eye health workers across the State of Victoria, I wondered what would become of eye care in Koori communities. Easy as it might have been to throw in the towel, approximately eight months into my field research the teams at OATSIH and VACCHO showed their resilience by beginning a new policy process. What lessons were learned from the shortcomings of past processes?

There is no doubt that delivering eye health care to Aboriginal communities is fraught with difficulties. One crucial lesson learned has to do with partnerships and collaboration. As I have demonstrated in a larger study of Aboriginal health policy (Kaplan-Myrth 2004), community–government relations gradually improve, and become more complex, as new participatory mechanisms evolve.

The importance of partnerships and collaboration extends to relations between the mainstream and the Aboriginal community-controlled health sector. Stand-alone eye health programs in Aboriginal community-controlled health services are not sustainable. Mainstream ophthalmology and optometry clinics are experienced by many Kooris as hostile environments. Neither segregation nor mainstreaming—opposite and extreme ends of a continuum—are appropriate models for Aboriginal eye care. Advocates from the Aboriginal community-controlled health sector and government bureaucrats have,

therefore, reached the mutual conclusion that better, collaborative relations need to be fostered between the mainstream and community sector:

> They're just not going to create a separate health system for the Aboriginal community. That's just not going to happen. There's not going to be two separate health systems in the one location. There will be, however, there will be, if you like, one… How can I put it? There will be one system that services different aspects. So you'll have an Aboriginal medical service that is there to pick up the gap that really can't be picked up by the rest of the mainstream system. So it is about accessing those mainstream systems. You wouldn't have an optometrist located in an Aboriginal medical service when there's an optometrist down the street. What you will have is an arrangement between the optometrist down the street and the Aboriginal medical service to ensure that people get access to eye treatment. That sort of stuff. *(Koori government bureaucrat)*

In some instances, expensive biomedical technology or highly specialised skills are required for prevention and treatment of eye disease. Primary eye care then runs into a problem because Aboriginal community-controlled health services do not have the capacity to meet those demands:

> The laser treatment for diabetic retinopathy could be done in an AMS [Aboriginal Medical Service] if they had the other equipment that's required, or it could be done in a government hospital, if the equipment were there. What's happened in some places, which is really silly, is the AMS has gotten the funds to buy the laser but they don't have the funds to buy the slit-lamp that the laser needs to be used through. And that slit-lamp is in the local hospital that would be available, but there's not been that discussion to say, 'Let's put our laser with your slit-lamp so that our patients can get treated'. *(Non-Aboriginal ophthalmologist)*

Some of these hurdles might be avoided if the Aboriginal community-controlled sector and the mainstream health sector were to work collaboratively. With the renewal of the Aboriginal eye health program, Aboriginal community advocates and government bureaucrats have proposed a model in which regional coordinators facilitate this sharing of skills and resources. These regional coordinators would ideally play the roles of cross-cultural and cross-institutional mediators.

But would the regional coordinator be totally divorced from inter-community, inter-professional and inter-governmental politics? Not likely. It is essentially impossible to choose a regional coordinator who does not have one bias or another. Old prejudices and misunderstandings about the Aboriginal community-controlled health sector lead some non-Aboriginal bureaucrats and medical professionals to argue that the regional coordinator should have no ties to Aboriginal community-controlled health services:

> Bring the four groups together: the AMS, the government hospital, the ophthalmologists and the optometrists, and have them coordinated

> by the regional coordinator… If the coordinator is tightly held by the [Aboriginal Medical Service] then they just become another tool of the AMS fighting against the mainstream community, against the government, against the hospitals, and they don't become effective. *(Non-Aboriginal ophthalmologist)*

From a community-controlled perspective it is undesirable to choose a regional coordinator who is outside of community politics, for that would imply hiring a non-Koori. There are clearly issues that need to be sorted out before the regional coordinator model is implemented.

A related issue that has come out of the analysis of the mainstream Australian health system is that high rates of Aboriginal illness and disease, including blindness, can only be reduced through proactive work in the social sphere. All the vision-screening, antibiotics and corrective surgery that can possibly be offered in medical clinics amounts to very little in comparison to the work that needs to be done to overcome colonialist history and Australia's ongoing, systematic discrimination against Aboriginal people:

> It's not to do with medical science; it's to do with social science. The reason the Aboriginal people won't use the optometrist down the street is not because the optometrist doesn't know how to treat Aboriginal people. At the end of the day, an eye is an eye is an eye. We all have the same human physiology. The reason why they don't use it has to do with historical and social barriers, not to do with science. So we have to deal with this at a social level. And that, as I said, means setting up an arrangement between the Aboriginal Medical Service and the optometrist so that people get serviced. That's a social remedy. That's not a scientific one. *(Koori government bureaucrat)*

Keeping Sight of the Bigger Picture

Although the Aboriginal eye health program in Victoria was not sustainable and the national and State-level Aboriginal eye health policy processes were short sighted, Aboriginal eye health policy and politics have made significant gains in the past five years of work. The concept of eye health was once unknown in Koori communities, but it is now a subject of lively debate among government bureaucrats, health professionals and advocates from the Aboriginal community-controlled health sector:

> I think [the eye health program] did a number of things: It raised awareness within the communities about eye problems, particularly in relation to diabetes. It also provided Health Workers with information on a whole range of eye health problems and issues. It provided VACCHO with the resources, capital and equipment to be able to loan out to our orgs [organisations] to use as needed. *(ACCHS executive officer)*

At the end of my discussions with policy makers and Aboriginal community advocates about Aboriginal eye health, I asked people what they envision for the

future of Aboriginal eye health policy and programs. The directors of Aboriginal community-controlled health services suggest that if they had the skills and other necessary resources they would run eye clinics on a regular basis:

> I would like to see the camera come here every three months... Because you're not going to catch everybody at once. You could organise it six months in advance so that it's in concrete. But then, on the day that it comes, there could have been a death in the community in Lake Tyers and there's no one left in this community. So I think it has to come here a couple days, like two or three days, and plenty of notice, make sure the co-ops are well prepared. And, yeah, it has to come into the co-ops. The staff have to be trained… So, yeah, I think it has to come on site on a regular basis. Everybody rotates around. *(ACCHS director)*

Koori Health Workers and non-Aboriginal nurses in community-controlled health services reiterate that Aboriginal health is all about 'opportunistic medicine'. In order for primary eye care to become a reality rather than an ideal, local health services need to have resources at their finger-tips:

> We need [a retinal camera] in the area. Say it's kept here: [Other communities] can ring and say, 'Can we get the camera next month?'. It's called opportunistic medicine. And this is the way health centres are going. We're no longer becoming band-aid stations. We need to swing to preventative medicine and become opportunistic. We need to grab them and say, 'Listen, while you're here, we've got the camera. I'd like to take a photo of your eye.' That's how I see it. *(Koori Health Worker)*

Government bureaucrats and health professionals agree that Aboriginal eye health is just one small component of a much bigger picture:

> We still have, too often, people diagnosed with diabetes way down the track when they've probably had it for years and it only emerges when they have these complications coming up. Our aim is to try and shift that. So the eye health needs to be seen in that broader context of primary health care and of chronic disease management. *(Non-Aboriginal government bureaucrat)*

Some Aboriginal political advocates caution that even though primary health care, holistic models of health and self-determination in health policy processes are Aboriginal communities' ultimate goals, those goals will take many more years to achieve. Until that time, Aboriginal community-controlled health services should continue to run whatever programs they can. The fear is that people's long-range goals might interfere with a community's imminent needs. Again, the message is to keep sight of the bigger picture:

> There's a real difficulty with the holistic paradigm: you run the risk of throwing the baby without [*sic*] the bath water, or cutting off your nose to spite your face… Sure, you can put together a sand painting

> and link all of health issues and all of social issues, all education and employment issues around law and around land, saying 'until we get land, nobody's going to get better'. But that doesn't mean you shouldn't work on immunisation or diabetes or eye health or sanitation or something—a component—while you work on the larger thing. *(VACCHO representative)*

A Koori government bureaucrat made the following comment during a discussion of Aboriginal eye health policy:

> There is a larger social agenda, I suppose, that underpins all of this. It's about, at the end of the day, there are twenty million people living on this continent and none of us are going anywhere. We have two choices: We can either pretend the other one doesn't exist. That's not going to work. Or we can say, 'Like it or lump in, we're all in this together. We need to get on.' It doesn't mean we have to be on each other's Christmas card list, but we've got to stop this pettiness and fighting with each other. And, I suppose, this in one sense tries to deal with that, too. This is only the eye health program. But, if an optometrist in a town suddenly learns the name of the Aboriginal people who walk past his office every day, that's a small win, that's a small gain. That's the sort of larger social agenda behind all of this. *(Koori government bureaucrat)*

Aboriginal Australians are no longer willing to accept government paternalism. This is reflected in Aboriginal people's responses to Aboriginal eye health policy:

> I don't think the eye health program is paternalistic to any greater or lesser degree than any other program. I think that's part of what we need to recognise, too. The paternalism exists, inherently, within our system. *(Koori government bureaucrat)*

Aboriginal political leaders and representatives from the Aboriginal community-controlled health sector seek to engage in partnerships with governments and non-Aboriginal people, but they do so with an air of caution; centuries of colonial history are not easily overcome.

Despite government commitments to engage with Aboriginal communities and organisations as collaborators in health policy, eye health programs are developed through top-down processes. The outcomes of eye health programs in Aboriginal and Torres Strait Islander communities are influenced by imbalances in decision-making power, professional interests, unsustainable infrastructure and resources, and lack of attention to regional differences in the needs and capacities of those communities.

For the above reasons, Aboriginal people do not get excited and express high hopes every time a government bureaucrat or non-Aboriginal health professional shows up at the door-step. As one person aptly comments:

> One wonders why they don't celebrate the Commonwealth's arrival [laughing]. There's no big party, 'Yes! The eye health team is here!' *(Non-Aboriginal government bureaucrat)*

Mechanisms still need to be improved in the public health arena to ensure that Aboriginal community-controlled health organisations have the opportunity and capacity to design and deliver culturally appropriate, geographically appropriate, sustainable health policy and programs.

That said, there is a great deal to celebrate with respect to the achievements in the Aboriginal community-controlled health sector, and there are myriad reasons to be excited and hopeful about the future of Aboriginal health policy and politics.

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