Abstract

Objective: This paper asks whether Indigenous health policies might be improved if governments listened to Indigenous voices, both Australian and those who drafted the Declaration on the Rights of Indigenous Peoples, 2007.

Methods: A fundamental tenet of the Declaration, which Australia endorsed in 2009, is respect for Indigenous knowledge and voice. The author analyses legal, cultural and historical sources for evidence of this respect. The metaphorical and empirical framework of the analysis is the epidemic of otitis media among Indigenous children.

Results: A survey of Indigenous advice about health clearly demonstrates that access to their land and respect for the diversity of Indigenous cultures should inform health policies. Despite, however, claiming to consult Indigenous peoples, policy-makers have not been listening. In many Indigenous languages not listening, or ‘bad ears’, has connotations of disrespect.

Conclusions: By turning a deaf ear to Indigenous knowledge governments are undermining any respect Indigenous peoples may have for them and their policies. A new approach is needed.

Implications: The Declaration on the Rights of Indigenous Peoples can provide federal, state and territory governments with benchmarks against which health policy can be developed and implemented. Authentic consultation could restore Indigenous confidence in government policies.

Keywords: policy - ear health - otitis media - Indigenous - culture - justice
Otitis media

From the first moment when the lora shouted ‘Warra! Warra!’ (‘Go away!’) to Captain Phillip [1], the non-Indigenous governing forces of Australia have suffered from binang gurri', bad ears, an inability to hear the Indigenous voice. This deafness continues to undermine the success of government health policies for Indigenous people. This paper argues it is time, and timely, to listen to the people. Australia’s announcement in April 2009 of formal support for the Declaration on the Rights of Indigenous Peoples provides the opportunity, and the framework, to address policies especially those aimed at the epidemic of chronic middle ear infections (otitis media), the major cause of permanent hearing loss which affects more than 90% of Australian Indigenous children in some areas of the country [2].

The lora were protective of their spiritual and temporal lives, and of the physical resources such as fresh and salt water, plants, animals, and geological features (including minerals) which sustained those lives. Even the most virulent of the early English critics of the Aboriginal way of life noted their superb physical fitness, for example, Watkin Tench wrote in the first few months of 1788, ‘in their persons, they are far from being a stout race of men, though nimble, sprightly and vigorous’ (p51) [3]. Exactly a hundred years previously, William Dampier had made similar observations on the north-west coast of Australia: the Aboriginal people were ‘of good stature but very thin and lean’ (p248) [4]. On 24 May 1788 however, four months after the arrival of the First Fleet, Dr George Worgan, surgeon on the Sirius, observed:

‘the constant appearance of the Excrementitious Matter of the Nose which is collected on the upper pouting Lip, in rich Clusters of dry Bubbles, and is kept up by fresh Drippings…’ (p92) [1].

Though other strangers had recorded previous visits to the continent, Worgan’s appears to be the first which directly relates to the major cause of otitis media, the ‘common’ cold, where runny noses can lead to inflamed ears and pressure on the eardrums which burst. As there were fewer foreign visitors to the east coast than to the west, it is possible that colds, and other infections such as measles, had been brought by the First Fleet or by La Perouse’s French expedition which had moored at Botany Bay in the first weeks of 1788.

As exogenous diseases made their way across the continent, people fell ill to them. Distance and desert slowed their progress: even within living memory Indigenous peoples can remember times without particular sicknesses (p119) [5]. In the 1960s a high incidence of chronic otitis media was observed shortly after the

1 Quandamoopah language of the Noonuccal nation of Stradbroke Island

Pintupi people emerged from the Western Desert and started living in artificially constructed communities [6]. A Pintupi elder was reported as referring to that time as ‘when the pus started coming out of the kids’ ears’ (p9-10) [6].

Chronic otitis media is rare in first world countries. However in 2004 the World Health Organization noted that the prevalence of eardrum perforation due to infection among Australian Aboriginal children was the highest in the world (28–43%) and urgent attention was needed to deal with this massive public health problem [7]. In 1995 Stuart, in his paper on the history and epidemiology of ear disease in Aboriginal children, described the high incidence and prevalence of otitis media as a huge problem which required a primary prevention strategy as well as studies of risk factors which predispose the children to the disease [8]. The April 2010 Overview of Australian Indigenous health status [9] reports an overall prevalence of recurring ear infections of 20% for Indigenous children between birth and 11 years. The prevalence is up to 40% in some communities.

If this degree of infection were found among white children there would be an immediate cry of ‘epidemic!’ from the media, and a swift response from government. Even the threat of an epidemic has created powerful campaigns against infections such as AIDS and swine flu, neither of which was likely to cause serious outcomes in more than 5% of Australians [10] [11]. However, apart from remedial measures, such as hearing loops in schools, caps with fitted hearing aids, and the nose blowing campaigns, governments’ responses to the causes of Indigenous hearing loss have been intermittent and ineffective.

Schoolteachers at Oenpelli observed the epidemic of Indigenous hearing loss as early as the 1960s [12]. Stuart [8] refers to detailed studies of ear disease in Indigenous children published in the Medical Journal of Australia. These studies by Clements in 1968 [13], and Stuart et al. in 1973 [14] and 1975 [15] showed higher than expected hearing loss. However the first empirical work available to the general public was that in Dr Archie Kalokerinos’s 1974 book Every Second Child [16]. In his medical practice in western NSW in the early 1970s Kalokerinos had found an unbelievable incidence of otitis media among Aboriginal children: in one month he saw 297 cases among 400 outpatients at Collarenebri Hospital [16]. He noted that it was common for medical practitioners to accuse Aboriginal mothers of neglect for not taking their children for treatment sooner, despite many children not complaining of overt symptoms such as an earache [16]. The conventional medical wisdom was that the causes of otitis media were parental neglect, poor hygiene and the Indigenous way of life. Kalokerinos disputed this: while inadequate parental care, lack of hygiene, overcrowded living conditions and passive smoking made matters worse, children still caught the infections more frequently and severely than other infants even when in ‘white’ care, for example in hospital with the best of hygiene and nutrition [16].
In his book Kalokerinos expressed his belief that there was a causal connection between ill health and being taken from their land. In a time where the Indigenous voice was silenced, especially in rural areas, the fact that Kalokerinos listened to his patients and understood culture was appreciated by Indigenous people. After he left western NSW, ‘Mum Shirl’, one of the founders of the Redfern Aboriginal Health Service, reported that there was a concern that ‘Aboriginal people around there wouldn’t trust any white people’ (p247) [5].

Studies had suggested a number of risk factors for Indigenous ear disease including exposure to cigarette smoke, lack of immunity, overcrowded housing, and bottle feeding. Kalokerinos’ analysis however was the first to focus on the human rights implication of the connection between place and illness [16]. In his view, bodily and spiritual illness was engendered by removal from country. One of the consequences was loss of access to nutritious bush tucker and handed-on knowledge about the ‘old ways’ of healing. Propensity to illness was exacerbated by the stress of living in an unfamiliar environment on missions or the edge of town. He believed that the inherited or genetic lack of immunity to exogenous viruses could be overcome by high doses of vitamin C.

In topography, Kalokerinos saw a further, and related, causative factor of otitis media. Some areas, mainly inland, seemed to predispose to running noses [16]. Certainly there is emerging evidence that the geographical factor is relevant. An unintended consequence of governments putting swimming pools into remote communities to provide recreation and an incentive to get children to attend school [17] has been an improvement in children’s ear and eye health [18]. A large-scale research project has recently begun on the health benefits to Indigenous children of saline swimming pools [19].

These causative factors are of course interdependent. On their country people have a balanced diet which includes fruits high in vitamin C and medicinal plants such as the red eugenia whose berries were roasted and the juice squeezed into the affected ear. Before they were moved off their land to make way for cattle, freshwater people had access to their lakes, waterholes, rivers and lagoons. Saltwater people had the sea. In the Indigenous worldview there is a connection between dispossession, depression and illness. A holistic approach to health requires the acknowledgment of the underlying wrong - the taking of their country. Nevertheless, even if the Cooperative Research Centre study confirms the healing properties of water, it is unlikely that there will be an apology for stolen land. Governments may find it cheaper and more politically expedient to construct more community pools than to return Aboriginal land and water.

As it stands Indigenous and non-Indigenous views of the causes of ill health seem irreconcilable. Rather than disputing causation of ill health, could the parties use international human rights conventions as a common meeting ground?

A human rights approach

By and large domestic law has proved ineffective in challenging decisions made by policy-makers to prioritize (or neglect) particular issues affecting Indigenous people [4]. Even anti-discrimination legislation is not ‘intended to control the manner in which a government [seeks] to gather information or undertake research designed to enable it to formulate its policies’ (p6) [21]. Would governments develop a more effective approach if they were prepared to acknowledge that there are different ways of seeing the world?

Australia is a signatory to a number of human rights conventions that refer to the right to health care [3]. However these conventions are not legally enforceable in Australia unless they have been incorporated into domestic law. Most international human rights conventions do not have force in Australian law; they are only persuasive as a means of informing government policy. Academic commentators however such as Natalie Gray and Ross Bailie from the Menzies School of Health Research, Northern Territory, and Larissa Behrendt, Professor of Law at the University of Technology, Sydney, have suggested ways in which international human rights law could be used to improve Indigenous well-being.

Gray and Bailie argue that rights derived from the international treaties, which Australia has signed, place both moral and legal obligations on governments to respond to Indigenous health issues [28]. Unfortunately, while politicians are cognizant of international condemnation of Australia’s human rights record, their fear of the electorate at home often overrides any imperative to advocate rights for Indigenous peoples. The second arm of government, the policy-makers and administrators, claim that the social determinants of ill health such as dispossession of land and resulting poverty are outside their jurisdiction. The authors

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2 The WHO considered that the ‘certain races, such as the South-western American Indians, Australian Aborigines, Greenlanders, and Alaskan Eskimos’ (p13), were predisposed to chronic suppurrative otitis media, and that they were at especially high risk [7]. Prior to the 18th century invasion Indigenous peoples were virtually isolated on this continent for at least 12,000 years, and it is an uncontroverted fact that isolated groups develop their own genetic inheritance. More than 40 years after Clemens’ paper [13] very little genetic research has been done on Indigenous lack of immunity to the diseases which cause otitis media.

3 Unfortunately he did not provide details in his book of which areas he thought were more affected than others.

4 For example, Cubillo v Commonwealth, 2000 [20].


6 For example, Koowarta v Bjelke-Petersen, 1982 [25]; Minister of State for Immigration & Ethnic Affairs v Ah Hin Teoh, 1995 [26]; and Re Kavanagh’s Application, 2003 [27].
conclude that indigenous health outcomes are better in those countries, such as New Zealand and Canada, where governments have treaty obligations to discuss issues of power and autonomy with their Indigenous peoples. Australia, on the other hand, has forced its peoples into an adversarial battle for cultural and native title rights. These legal battles exclude discussion of matters such as health. Gray and Bailie suggest that sustained advocacy for the promotion and protection of human rights, such as those of education and housing, will ultimately demonstrate the structural inequality which underlies ill-health.

In the same vein Larissa Behrendt had earlier argued that non-Indigenous Australians decontextualise the socio-economic problems of Indigenous lives by disregarding the genocide, dispossession and discrimination and focussing on a model of disadvantage. She suggested that Indigenous Australians could use the language of international human rights to communicate to non-Indigenous people about those institutions which continue the harm suffered by the colonisation process. Because the conventions apply to all Australians they could provide a benchmark against which to measure progress towards rights which others take for granted, for example, adequate health services [29].

Behrendt’s approach can be demonstrated in two relevant examples from the Australian Human Rights Commission. In its 1997 Bringing them home report the Commission stated, ‘Hearing loss is endemic in Indigenous children and linked to poverty’ (p549) [30]. This places the focus of causation squarely on the disadvantages of being poor with its connotations of limited access to medical services, overcrowding in housing, and the issues noted by medical practitioners in Kalokerinos’s time. Poverty as a cause engenders helplessness both in the victims and the policy-makers. However in its recent submission to the Senate Inquiry into Australian hearing health, the Commission shifted to a rights-based analysis [31]. It advocated setting targets and health indicators based on the rights expressed in international conventions such as the Conventions on the Rights of Persons with Disabilities, 2006, and the Rights of the Child, 1989. These rights apply to all Australians and can provide standards which can be measured and monitored.

The Declaration on the Rights of Indigenous Peoples, 2007

I would like to take the above suggestions to a practical level. Two of the enduring features of health policies for Aboriginal and Torres Strait Islander peoples have been governmental lack of consultation and its concomitant inability to seek consent to those policies. A recent example is the Northern Territory Intervention, designated as programs to protect the health of Indigenous women and children [32]. The Declaration on the Rights of Indigenous Peoples might provide a framework for a more practical approach to effective and culturally acceptable health policies.

Drafted by peoples who were shifted off their land, and sent to school, church and work without their agreement, two of the basic assertions in the Declaration on the Rights of Indigenous Peoples, 2007 are the rights to be consulted about matters which affect them, and the giving of consent to legislative or administrative interference in their lives [33]. It is the right to consultation which I propose to focus on in the remaining part of this paper.

In its more than 20 year passage towards the United Nations General Assembly, the Declaration on the Rights of Indigenous Peoples faced hostility, savage amendments and last minute obfuscation, especially from Australia, Canada, the United States and New Zealand, the four Nation States which ultimately voted against it in 2007. By endorsing it last year, Australia is now proclaiming to the international community that it is willing to listen to Indigenous peoples.

The Declaration is necessarily a compromise document. It is not a Convention, and it is not legally binding on its signatories. However its unique contribution to international law lies in its assertions of Indigenous values and expectations. Underpinning the Declaration are the key demands for the recognition of the relationship between Indigenous peoples’ land and their well-being; respect from others; consultation and active engagement in government and non-government programs which affect Indigenous peoples; rights to maintain and transmit culture; and rights to economic and social development.

As for the issue of respect for the indigenous voice in the formulation of health policy, Article 24(2) of the Declaration asserts that indigenous individuals have both an equal right to the enjoyment of the highest attainable standard of physical and mental health, and an expectation that Nation States will take the necessary steps to achieve the full realisation of that right. More pertinently to the epidemic of hearing loss, States are expected to take effective measures, including special measures where appropriate, to ensure the continuing improvement of indigenous children’s health [33].

Turning a deaf ear

The importance of the Declaration in the context of health programs is its reference to respect for Indigenous knowledge and culture [33]. I suggest that failure of many past and present health policies might be that policymakers have not listened to the Indigenous voice.

In oral societies good hearing is highly prized. The particular value placed on listening is reflected in many Australian Indigenous languages where a person who is not responding to what they are told, or is not receptive to teaching, is said to have ‘bad ears’.

7 For example, binan goonǰ in the Bidjara language of South West
Karen Martin, a researcher from Minjerripah, Stradbroke Island, writes that in her language, Quandamoopah, binang gurri (bad ears) has connotations of disrespect for others [35]. Thus a person who is called ‘deaf’ is not willing to learn, and is wilfully refusing to listen. According to the anthropologists, Ronald and Catherine Berndt, such a person can be subjected to ridicule, not taken seriously, excluded from working with others, classed as stupid or recalcitrant and may even be shunned, for example, in ceremony or courtship processes [34]. This treatment may be contrasted with loss of sight: the blind are treated with the utmost solicitude.

A further connotation of ‘bad ears’ is persistence in wrong thinking in the face of evidence. Therefore the concept that policy makers are binang gurri has serious implications for how Indigenous people assess the effectiveness of the consultation processes which are meant to underpin government Indigenous health policies. When Indigenous peoples spend time and effort on recommendations only to have them disregarded, respect for government falls away:

‘Every time Government officials come to Yuendumu to ‘consult’ with us, they don’t listen to us. They just tell us what their plans are. When any of us speak up about our concerns, it’s as if they have deaf ears. They just go on with their plans as if we had said nothing. There is no communication. They treat us like kids.

We are proud Warlpiri people. It is a great insult to be treated like this.’[36]

Listen up to the voices

Binang gurri is not a new phenomenon in Indigenous policy making. For many years Indigenous leaders and writers have been making two major points, neither of which has been listened to. Firstly, they have argued that a uniform health policy no more fits the diversity of Aboriginal nations and peoples than would one policy work for the whole of Europe. Primarily however they have said time and again that access to country is fundamental to physical and spiritual health. Every contributor to the seminal 1982 work Body, Land and Spirit [37] found that current Indigenous health programs were not working because governments refused to hear about the connections between land, health and spirit. In 1977 Kevin Gilbert interviewed people for his work Living Black. They reported that black-controlled health services were effective and had a positive impact on Indigenous people, and that the old ways and bush medicines were best [5].

Statement, presented to Prime Minister Bob Hawke in 1988, called for recognition of the rights to medical care and ‘to respect for and promotion of our Aboriginal identity, including the cultural, linguistic, religious and historical aspects…including the right to be educated in our own languages and in our own culture and history’[38]. Eleven years later Patrick Dodson, the Chair of the Council for Aboriginal Reconciliation, was of the view that Indigenous peoples’ rights, including the right to determine priorities and strategies involving health programs, should be in a legally enforceable treaty [39]. In his first report as Social Justice Commissioner, Mick Dodson argued that it was ineffective to suggest that just because Indigenous peoples share a common bond of being dispossessed of their land that they should be treated as if they are one single group. Nor could their health issues be solved in the same way as non-Indigenous health problems because they have different causes. What was required was self determination:

‘The aim is not merely to participate in the delivery of community services, but to penetrate their design and inform them with indigenous cultural values. The result is not merely services which are better structured to reflect the needs and identity of particular communities: there can be a resultant improvement in the effectiveness and efficiency of these services’ (p56) [40].

Underpinning all of these arguments is the insistence that the root cause of poor health is dispossession of land to which Indigenous peoples have spiritual and religious ties. Galarrwuy Yunupingu, then chairman of the Northern Land Council, put it bluntly in 1987 when he said: ‘land rights…gives us the basis for…achieving proper health’[41].

A most extraordinary example of binang gurri was the deafening silence which met the foreword which John Newfong wrote for the National Aboriginal Health Strategy in 1989 [42]. His work, Aboriginal Australia – the reality and not the myth, clearly sets out the knowledge and guidelines necessary to shape health policy. Given it was commissioned as a preface to yet another government strategy, the fact that its advice has been ignored suggests it was not what the federal government wanted to hear.

Newfong made the same two points: a uniform approach to health policy cannot work because of the enormous diversity of peoples and situations. Not only were there hundreds of Aboriginal nations at the time of conquest, but their societies were changed when white people penetrated Australia and killed whole groups of Indigenous peoples. The rest were sent to cities for ‘civilisation’ and ‘domestication’, or forced to live in closed settlements on the edges of towns under appalling living conditions. The cohesion of societies was further damaged by the infiltration of the conquerors’ values, such as Christianity [42]. Therefore general standards could not be applied; nor could there be generalised assessments of the extent to which a particular health program may be effective. In Newfong’s view, a ‘one size fits all’ national Indigenous health...
policy was characteristic of a rigid bureaucracy lacking creativity.

Without land, Indigenous rules once applicable for healthy living can no longer be applied. So secondly and fundamentally, Newfong argued that land rights is the sovereign issue in health policy - sickness is caused by people being taken off country to make way for pastoralists and developers. Pre-empting the swimming pool findings, he quoted the eminent ophthalmologist Professor Dame Ida Mann who, when asked in the 1930s about prescribing drugs for Indigenous illness, had replied, ‘Drugs? I’d prescribe water’ (pvi) [42].

However, like the kids in remote communities who have been given caps with hearing devices but readily lose them, or throw them away, policy-makers have not benefited from consultation and advice. As we say in English, the cry for respect for the wisdom and diversity of Indigenous knowledge, and for the return of land, seems to ‘have fallen on deaf ears’.

The effects of hearing loss

For at least a quarter of a century Australian governments have responded to the crises in Aboriginal health by drafting generalised policies aimed at reducing the measurable disparities between Indigenous and non-Indigenous life expectancies. In this flurry of activity, the epidemic of otitis media seems to have been marginalised. One has to ask why, when good hearing is fundamental to educational and employment prospects - both issues high on governments’ agendas. Another issue which exercises governmental minds is the over-representation of Indigenous people in custody and high suicide rates. It was noted nearly 20 years ago by the Royal Commission into Aboriginal Deaths in Custody that there may be a connection between hearing loss and criminal behaviour [43], yet this issue remains insufficiently investigated.

The hearing loss suffered by up to 50% of the children who now make up half of Australia’s Indigenous population creates an adverse effect on the transmission of culture and the authority of the elders. Elders say that the young ones are not showing them respect: a person with ‘good ears’ listens and regulates their behaviour. But if the young ones are deaf, they cannot hear the elders. The cultural rights to transmit language, songs, stories, dance and ceremony, and the testing and advancement to a higher level of knowledge (including healing skills) are impaired by hearing loss. Article 8 of the Declaration imposes an obligation on Australia to:

provide effective mechanisms for prevention of, and redress for any action which has the aim or effect of depriving [Indigenous peoples] of their integrity as distinct peoples, or of their cultural values or ethnic identities (Article 8.2a) [33].

Conclusion

Clearly health policies devised by governments are not working fast enough. The ‘gap’ has not been closed. The ‘gap’, a simplistic concept, actually represents lost lives, pain and suffering, and frustrated opportunities. The high prevalence of otitis media is a devastating example of this. Binang gurri means that governments have failed to hear what Indigenous peoples say is necessary for adequate Indigenous health policies – a holistic approach which encompasses spiritual as well as physical health.

The Australian government’s acceptance of the Declaration on the Rights of Indigenous Peoples creates an opportunity to shift focus and create health policy frameworks based on respect, listening to the Indigenous voice, and access to land. Authentic consultation in health policy development and implementation would help restore Indigenous confidence in government. Instead of blaming Indigenous people, or simply providing remedial devices, it is time to listen up.
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