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### **Submission**

Concerning the Health Status of Aboriginal Women for the development of the National Aboriginal Women's Policy.

It is of concern that the infant mortality rate for indigenous children is still three times that for non indigenous children. Contributing to this mortality is the presence of foetal alcohol syndrome and mothers who smoke during pregnancy. The first comes about by drinking mothers whose baby becomes maldeveloped and is at risk of being born prematurely or even born dead or dying later.

The second sees the ingredients of tobacco smoke asphyxiating the baby before birth and how that baby comes to be small at birth and like many low birth weight babies is at risk of dying at or after birth but also developing many chronic diseases if it survives into adult life.

I argue that both stem from social breakdown amongst Indigenous women when they become pregnant at too early an age and aren't able to recognise the risk factors that will affect their babies.

These girls were born of generations where women in late pregnancy were removed from their communities to obstetric centres to give birth. Not infrequently these centres were and are hundreds of kilometres away. Such an intervention destroyed the traditional process of birth in which the women of the family were intimately involved and afterwards the men.

The absence of the mothers created other disruptions, whereby men took other sexual partners and the children left behind sometimes found themselves neglected. Those children born away from their land had nothing official to indicate their attachment to it.

In short, the evacuation of pregnant women for birth outside their country may have been well intentioned, but has been an important factor in creating a society where so many pregnant girls engage in behaviours that put their unborn babies at risk of dying.

### **Recommendations**

1. That Aboriginal women at low risk of complications be confined in or near their own country and that facilities such as the provision of midwives be made available for this to happen.
2. That Aboriginal babies born to mothers evacuated from their country for delivery should have the name of their country entered on their birth certificates.

20/10/2009

JILPIA N JONES

### Timing of transfer for pregnant women from Queensland Cape York communities to Cairns for birthing

John W Cox

**TO THE EDITOR:** More than 30 years ago, I was employed by the Commonwealth Government's Maternal Mortality Committee to identify and evaluate factors contributing to maternal and infant mortality among Aboriginal Queenslanders. At that time, government policy was to transfer all pregnant Aboriginal women from their rural communities or missions to Cairns Base Hospital at 32 weeks' gestation until 7–10 days after birth.

Findings I presented in a report to Queensland Health in 1977<sup>1</sup> and at the Australian College of Paediatrics Annual Meeting in 1979<sup>2</sup> included:

- Babies of women who were compulsorily transferred at 32 weeks' gestation to Cairns Hospital had lower neonatal death rates. It was assumed that — as Aboriginal women had unreliable gestational age assessments, antenatal care was irregular, and birthweights were lower than for other races<sup>3</sup> — the risk of premature deliveries could be avoided by early transfer.
- There was a lower rate of breastfeeding among mothers transferred to Cairns, largely because if they opted to bottle-feed they could return home after 3–4 days (rather than waiting 7–10 days in Cairns to ensure breastfeeding was established).<sup>1</sup>
- Growth failure was common in the month after weaning.<sup>4</sup>
- Bottle-fed babies experienced slower weight gain and higher rates of illness.<sup>5</sup>
- Suboptimal growth in bottle-fed babies during the early postnatal months predisposed babies to poor growth patterns during infancy<sup>6</sup> and increased death rates.<sup>7</sup>
- Women returning to their communities took with them infections acquired during the hospital stay in Cairns.
- Separation anxiety or maternal deprivation was common among children left in their communities.
- There was decreased family bonding (eg, between the father and the new child) and sibling resentment at maternal separation.
- There was unquantifiable resentment at having babies born away from the ancestral lands.
- Women delayed admitting their pregnancies in an attempt to remain in their communities, resulting in fewer antenatal visits.

The antenatal transfer policy has been in effect for 30 years, despite conflict between those who were predominantly concerned with maternal and perinatal mortality (who favoured compulsory delivery in Cairns Base Hospital), and those (myself included) who were concerned about the effects on children's growth and development.

During this time, I have observed weakening family and community bonds, increasing alcohol and substance misuse and sexual abuse, low school attendance, poor employment records and domestic violence. My studies of Aboriginal and non-Aboriginal children born in Cunnamulla in western Queensland followed the same cohort of children from birth<sup>8</sup> for 20 years.<sup>9</sup> The presence of a father who was employed at the time of the child's birth acted as a role model for the future and was more effective than all other social interventions with respect to the child's successful education or employment 20 years later, irrespective of race or subsequent social support or interventions offered to the child during school years.<sup>9,10</sup>

Arnold and colleagues' recent article in the *Journal* records a situation almost unchanged from 30 years ago, with the exception that antenatal ultrasounds have allowed transfer to occur at 36 weeks' instead of 32 weeks' gestation.<sup>11</sup> Enormous resources of goodwill, effort and money have been spent in these communities over 30 years, yet the family disruption, unemployment and abuse statistics remain at variance with the Queensland norm.

Perhaps the time has come to allow low-risk births to occur in selected towns, where the mother can be surrounded by her friends and relations, and be in closer contact with her ancestral land. I endorse the article by Arnold et al and hope they are more successful in implementing change than I have been.

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## Building health literacy in Australia

Don Nutbeam

*To empower patients, we need to apply the knowledge gained from research*

The final report of the National Health and Hospitals Reform Commission, *A healthier future for all Australians*, has rightly stimulated debate in Australia about what it takes to create an equitable and sustainable health care system.<sup>1</sup> The report draws attention to the importance of strengthened consumer engagement, boldly described as “giving people real control and choice about whether, how, where and when they use health services, supported by access to evidence-based information that facilitates informed choices”, as a platform for creating an “agile and self-improving health system”.<sup>1</sup> Building health literacy is identified as a key strategy that will underpin strengthened consumer engagement.

This ambitious commitment is long overdue. Research indicates that those who actively participate in health care decisions generally achieve better health outcomes compared with those who do not, and that most patients are not currently involved in health care decisions to the degree they would like to be.<sup>2</sup> Those most likely to participate in health care decision making tend to be younger, female and educated.

Regardless of personal preferences, not everyone is equally equipped to participate in health care decisions. The Commission's report recognises this in its advocacy of action to build health literacy. Health literacy can be simply defined as the *capacity to acquire, understand and use information for health*. A 2006 Australian Bureau of Statistics survey examined health literacy in Australia using data derived from the Adult Literacy and Life Skills Survey, which assessed respondents' prose and document literacy, numeracy, and problem-solving skills.<sup>3</sup> From these data, information relating to respondents' health literacy was derived, using specific questions related to health issues. The study found that 60% of Australians lack basic health literacy, described as the “minimum required for individuals to meet the complex demands of everyday life and work in the emerging knowledge-based economy”.<sup>3</sup> In a country that prides itself on achieving high rates of functional literacy, this is surprising, and indicates that individuals with higher levels of general literacy may not be able to consistently apply it in situations requiring specific content knowledge, or in an unfamiliar environment. For many individuals, as patients, carers and members of the public, health care settings are unfamiliar environments in which alien vocabulary and concepts are used.

The relationship between literacy and the quality and outcome of health care has gained increasing attention, especially in the United States.<sup>4</sup> Research shows that people with poor health literacy are less responsive to health education and use of disease prevention services, are less able to successfully manage chronic disorders such as diabetes and asthma, and incur higher health care costs.<sup>5</sup> This has led to progressive testing of interventions designed to mitigate the effects of poor health literacy through modified communication and improved health service organisation.<sup>6</sup>

The limited research on health literacy conducted in Australia, such as the article by Adams and colleagues in the current issue of

the *Journal* (page 530), confirms both the findings of the Australian Bureau of Statistics survey on the extent of the problem, and the established link between poor health literacy and poor health outcomes.<sup>7</sup> Research from New South Wales provided insight to the needs and preferences of people with low literacy in the development of clinical decision aids.<sup>8</sup> Given the policy recommendations and potential importance of their impact, this remains an underdeveloped area of research.<sup>8</sup>

Although the Commission's attention to health literacy is encouraging, the practical actions proposed in its report are underdeveloped and will require early attention to seize this opportunity for action. *Health literacy is best developed through education that is customised to individuals and their specific priorities*. The recommendation that health literacy be incorporated into the National Curriculum for school children is commendable; however, the educational needs of a person with diabetes who is receiving patient education, or a pregnant woman attending antenatal classes, or a carer of a person with long-term mental illness will be greatly different. School health education will not prepare us for the different individual health challenges we may face.

If we are to see “real control and choice about whether, how, where and when [people] use health services”,<sup>1</sup> three strategies are required. First, health care providers and those responsible for patient management and administration need to demonstrate greater sensitivity to the needs of patients with poor health literacy by creating a less alienating health care environment that is more responsive to patient needs. Second, greater care needs to be taken to improve the quality of patient communication and the materials that support it. Both of these strategies require further research, and both can be achieved in part through modification of basic and continuing education. Third, outside the health care system, as well as investing in school education, Australia would do well to follow the lead of the United Kingdom in adopting innovative adult education programs such as the Skilled for Health program, which brings health content into an adult basic skills program.<sup>9</sup>

It is over 15 years since national goals and targets for health literacy were first proposed in Australia.<sup>10</sup> Since then, our understanding of health literacy has grown considerably. If this knowledge is not applied, the policy goal of achieving meaningful control and choice by patients is unlikely to be met. Worse, increasing patient participation without specific interventions to address low health literacy could exacerbate existing health inequalities by further alienating those with poorer literacy skills and less confidence in using the health care system.

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