

I would like to acknowledge the generosity and spirit of the traditional owners of the land on which we meet. I pay my respects to the Dharug (Eora) people whose various bands included the Cadigal whose land is now occupied by suburbs including the Haymarket and Broadway, while the Wallumattagal were the ancestral peoples of the Ryde area. I mention the Wallumattagal as I will be speaking out at Epping tomorrow.

I confess to being an unsophisticated speaker and ask that you not be too disturbed by the issues I talk about. I recognise how confronting my talks can be and invite you to join in and contribute as you wish. There will be some overlap between the topics I introduce but the intention is to fit them together like a puzzle at the end of the session. Bear with me as I jump everywhere in my zeal to place as many issues as time allows into the discussion.

Australian of the Year 2003, Professor Fiona Stanley, correctly identified the poor status of Indigenous health as being breaches of basic human rights and therefore racist. In presenting the Vice-Chancellor's Oration at Edith Cowan University (21st March), Professor Stanley again pointed out that Indigenous children suffer markedly worse across a number of health and social indicators. We are all aware of these devastating statistics and also are aware that such indicators significantly underestimate the burden being experienced by Indigenous families and their children.

There is a direct and profound relationship between the neglect of human rights, Indigenous disadvantage and the failure of children to optimise equal life chances. Moreover the neglect of fundamental human rights fosters and sustains widespread dysfunction and violence.

The impact of history and the residual effects of racism and inequity continue to burden communities as shown by this diagram which I constructed from a population tree. As another generation is born into the same troubled environment, the aftermath of history and poverty remains constant, and this not only sustains but also magnifies poor social outcomes. The diagram also illustrates the community's dependence on the maternal economy, often grandmothers, whose own health becomes compromised with the burden of family dysfunction as they struggle to make ends meet on a pension while other family income may be used to satisfy addictions.

Indigenous community councils are at their wit's ends. Hard to procure funding is spent repairing damage by drunks and teenage vandals. Failure to assess or screen for substance related birth injuries have denied children the special structures and services which could potentially improve their quality of life and life chances. There are far too few special education teachers and early childhood specialists and for too many newly qualified teachers. Early identification and intervention is almost unheard of in most Indigenous communities in Queensland even when the signs of developmental disabilities are known as is the family histories of substance abuse across generations.

The high incidence of incarcerated juveniles still has not triggered alarm even when the same young people graduate into adult prisons. The child without empathy, unable to feel repentant and into criminal offending, is a well documented feature of poor brain development. As more affected young people are drawn to the excitement of the cities and towns, they attract the attention of the police. Racial profiling is rife as police routinely stop and question Indigenous youth simply because they are young and black. This, for the youth with an inherent dislike of police.

To demonstrate the violations of children's human rights, I will begin with some definitions, illustrate with a story, and then synthesise these to construct a final analysis. In so doing I must warn you that the presentation will be confronting as it substantiates that from a complex recipe of social and biological factors, a profound alteration has occurred in brain functioning. For Indigenous peoples, this can be directly attributed to several centuries of deliberate and cruel social engineering. Likewise, it can be argued that a comparable biological alteration has also occurred in non-indigenous families exposed to similar factors but through a different channel of social circumstances.

Unfortunately for afflicted families and individuals, the ongoing violation of human rights sustains another generation of at-risk children who then haplessly continue the cycle by reproducing yet another vulnerable population. In particular, I am referring here to the lack of recognition of the problem, suitable structures and customised education needs and services required by children exposed to teratogens in utero, that is, the second definition on the list shown here.

Food, shelter, protection, education, equality, etc. There is no keener revelation of a society's soul than in the way it treats its children (Nelson Mandela). The evidence of the way Australia treats its Indigenous children can be clearly noted in the increasing numbers of Indigenous children in detention centre.

Towards the latter end of 2002 I attended the funeral of a much respected matriarch. I noted there were twelve youths and adult in handcuffs whereas five years ago there would have been only one or two, maximum, so restrained at a funeral. From interacting with close family and friends of the detainees for the past 8 years, I knew that, despite appeals for help, the social and emotional behavioural problems of their life course continued undiagnosed even after they broke the law.

This outcome is not surprising given the lack of knowledge and services to cater for those disadvantaged by neurodevelopment factors and being born into a toxic society.

The hypothesis that sub-optimal birth conditions contributed to poor health outcomes in later life was brought to prominence by paediatrician, David Barker in 1988. In the next decade other researchers endorsed his theory including Peter Nathanielsz (1999). Nathanielsz promoted programming in the womb as being causal to chronic adult conditions such as obesity, hypertension and coronary heart disease.

More recently, there is discussion that prenatal famine may cause later antisocial behaviours and there is increasing recognition that substance use and abuse leads to irreversible developmental problems. A clear case of silage research, these findings have remained almost exclusively the property of medical researchers to the preclusion of those for whom the information may have had equal, if not greater relevance as well as providing a source of self health promotion.

The case of Phineas Gage is attributed as having alerted the medical world to the importance of the frontal lobes of the brain. According to the Phineas Gage Page (www.deakin.edu.au/hbs/GAGEPAGE/pgstory.htm), Phineas was a railroad construction worker in Vermont. On the 13th September, 1848, he accidentally drove a tamping iron, 3 feet 7 inches long, weighing 13.5 pounds, diameter 1.25 inches, under his left cheek and completely out the top of his head. The iron rod landed 25 to 30 yards behind him. Phineas was knocked over but is thought to have remained conscious even though most of the left frontal lobe was destroyed. He was hospitalised and returned home after 10 weeks.

After some months Phineas is reported to have returned to work but his personality had become a posionality. From a capable, likeable, well-balanced personality, he became

fitful, irreverent, and grossly profane, showing little deference for his fellows. He was also impatient and obstinate, yet capricious and vacillating, unable to settle on any of the plans he devised for future action. His friends said he was "No longer Gage."

After a stint in Bernum's Museum in New York and several other jobs, Phineas went home to his mother in 1859, developed epileptic fits and died in 1860.

The preconception and prebirth periods are crucial in determining the optimal brain and behaviour development of children. Such environmental influences are dependent on good paternal and maternal health, good maternal nutrition and absence of infections, drug use, environmental chemicals and any other physical restrictions or damage (eg hereditary influences).

The period in utero and the first three years (the early years) are the most rapid times for brain growth and therefore when the need for care, nurturing and comfort are at their utmost importance. However, as Professor Fiona Stanley, Australian of the Year and Director of the Telethon Institute for Child Health Research, stated in an interview on the Andrew Denton show, "Enough Rope", there is an epidemic of four to six year olds with behavioural problems due to early influences. "Their brains have become wired in such ways in their early life that they are not able, in fact, to behave normally."

A useful site to understand biological susceptibility can be found via the Danish Environmental Protection Agency's website. Briefly, to summarise their information on susceptible periods in human development and exposure to chemicals:

- Foetal damage is dependent on the substance, dose and state of maternal and foetal tissues at the time of exposure. Similarly damage varies according to dose/time points in both the gestational and postnatal periods producing different abnormalities or deficiencies depending on the chemical of exposure. (Dencker Eriksson 1998, Harris 1997, National Research Council 1993).
- The foetus is not protected from chemicals that enter the mother's body as the placental barrier is extremely permeable to chemical substances. In fact almost all substances foreign to the mother's circulation enters the foetal circulation.
- As foetal development progresses susceptibility also continues. To gain a clearer understanding of this process, in his book "Life in the Womb", Peter Nathanielsz (1999) produced his Ten Principles of Programming (see handout). If we look at the social engineering of Indigenous people over the past century, it becomes obvious that biological damage has occurred as a result of being forcibly taken from the diet of a hunter/gatherer to being dependent on sugar, tea, white flour and other foreign food served up on missions and reserves. The experience of such environmental factors in early life have an impact on the risk of specific diseases in later life. For example, we now know that low birth weights are at risk of becoming obese adults, that thinness and short body length at birth has been associated with the development of cardiovascular disease and non-insulin dependent diabetes.
- To these factors can be added exposure of the mother to stress and violence (Robin Karr-Morse & Meredith Wiley's "Ghosts from the Nursery: tracing the roots of Violence").

These subjects will be mentioned again in the presentation.

Tobacco correlates with low birth weight, pre-maturity, lung disorders and sudden infant death syndrome. Nicotine exposed children may experience delays and difficulties in performing the basic tasks of infancy such as eye contact, sucking and head turning... At school age, children of mothers who smoke may be at risk of poor reading skills, attention deficits, and hyperactivity. (p 69 – Karr-Morse & Wiley, 1997).

Following information from: (Schulz, www.medphorm.co.za/sapj/2002/april/pregnancy.html)

Anomalies in offspring of marijuana users

Severe epicanthal folds- unusual amount of skin over the nasal portion of the eye

Ocular hypertelorism - unusually wide separation of the eyes

Increased fine tremor & CNS excitation, hyperactivity & signs of distress ie signs of neonatal withdrawal

poorer visual habituation to visual stimuli (indicator of NS functioning & integrity)

low birth weight

Paint - increased spontaneous abortion, etc

Caffeine - widely overlooked (but use of Coke starts very early in life)

Deficiencies in these functions have mostly been attributed to prenatal exposure to alcohol but that theory is being reconsidered as perhaps prenatal exposure to addictive substances generally.

Children with poor executive control are easily stigmatised and often by the community itself in what I call "good kid, bad kid". Often too their parents are that child grown up and so develops a construction of "the other" where certain families are labelled and blamed. They are unable to learn at school, unable to reach any baseline of potential, grow emotionally and are likely to extend their disability. Essentially their poor executive control has not allowed them to develop sufficient emotional intelligence.

Daniel Goleman states the reverse condition is known as emotional illiteracy and can be calculated in the increasing rates of teenage mental illnesses, sexually transmitted infections, early pregnancies, youth suicide and juvenile crimes of violence including sexual assault and child abuse. The most common emotional disability that Goleman found among young girls was depression which increased significantly at puberty especially as eating disorders and was more prevalent among African American youth.

This story can almost certainly be extended to Indigenous Australian populations as well as non-Indigenous groups sharing similar socioeconomic status.

Young adults, with in utero exposure to teratogens, seriously compromised life courses, and being raised within a toxic environment without adequate nutrition, nurturing or social skills, are commonly prevalent factors among many of our families.

In *Ghosts from the Nursery*, from which the quote above was taken, the reader is reassured that environmentally protective factors can eliminate, or at least lessen, brain vulnerabilities if tackled early enough. This is the 'solid kid' concept that Aboriginal people aim for however the burdens of stress often overwhelm those who carry the load.

For the most seriously violent children, family has been the source of rather than the refuge from trauma. When children are terrorized by violence within their homes from an early age the results come back to haunt us. (p 124)

Elizabeth Tindle's work in raising awareness of foetal alcohol exposure over more than two decades, continues to frustrate her. The above paper, presented in 1994, gives the example of *Legionella longbeachae*, a naturally occurring soil bacteria, and now known as Legionella's disease. Following the deaths of several adults contaminated through potting mix, preventative action was rapid. All bogged potting mix had to carry health warnings. Education on alcohol consumption during pregnancy has received little attention and labels are still not placed on alcohol bottles as warnings.

Might the child exposed to alcohol in the womb, sue their mother for child abuse or for the damage they will have to carry through their life course? Could the mother sue her doctor for failing to advise her not to drink?

(Or Elizabeth Tindle, *Who carries the can?* 1994 - psychologist who works at QUT)

The Foetal Origins of Aggression, aggressive schooling, the multiple vulnerabilities associated with being marginalised and impoverished, without official recognition of identity, political expediency of the educated, and a host of other issues, has resulted in Indigenous generations being left behind socially and economically in Australia.

In the remaining time, let us run through some of the most damaging visual symbols of racism that continue to pervade nationally. These symbols, as well as inappropriate research methodologies which look at only a section of a community's profile, according to Johan Galtung, are culturally violating.

The lived interactions of community functioning are not accurately portrayed in morbidity and mortality statistics. The failure to identify these changes can be directly attributed to the practice of disciplines to work within silos. This archaic system of relying on morbidity and mortality data for the health of a population has vastly misinterpreted what is actually happening away from the hospital or health clinic.

Services who do not contribute to morbidity and mortality statistics are usually the areas where the greatest health and social problems are being handled, that is, in the schools, child minding centres, rehabilitation units, police stations, courts, juvenile justice agencies, detention centres, prisons and women's shelters. Outcomes relating to behavioural disorders have been completely overlooked.

Moreover, consultation processes have not shared up-to-date scientific research findings to allow the community to place their own observations into a scientific model. Thus the insidious and sinister nature of neurodevelopmental changes as a result of the historical and contemporary experiences, has been allowed to take hold and continues.

This emblem was replaced by a new symbol when the ALP under Premier Beattie came to power, however some are still displayed throughout government buildings including Parliament House.

Courts too still retain their British inherited symbols including wigged law professionals.

"fidelity between the deer and the bird?"

1927 - Daphne Mayo received a commission to carve the sandstone pediment over City Hall which she carved between 1931 to 1934.

The Robed State (central) is shown sending forth her squatters and explorers with their beasts of burden, the horse and the ox. Cowering and cast out to die (left hand corner) is an Aboriginal man and a kangaroo. The carving is described in the Brisbane Sculpture Guide as symbolical of the municipal life and development of the Greater City of Brisbane as, to the right - explorers, industries and the arts - to the left - "Pioneers advance upon retreating Aborigines and fauna".

Section of Cherbourg cemetery - plain wooden crosses now recently painted - note the absence of monuments that tend to dominate mainstream cemeteries.

All funerals, "the old wooden cross" is sung - sometimes several times and again at the graveside - obviously has intense meaning.

"...even in death..." recent removal of "decorations" on graves - plastic flowers and coloured glass in water-filled alcohol bottles and flagons

To what extent does this cultural icon violate those who do not subscribe to the imposition of British ideals?

Are the wounds of colonisation oblivious to those who support it?

Does the Union Jack have a place on the flag of a multicultural nation?

Should we not be mindful of everyone's origins and historical experiences?

Is this a case of British race privilege?

Is it relevant as an Australian flag even if many Aboriginal people still refer to the Union Jack as the butcher's apron'?

To end on a political note

We all know families where, from out of the most profound dysfunction, there are not only survivors, but people who do very well. How do we make that happen right across the community?

Clearly, we need to remove every trace of racism, every inequity. That's the challenge but, given Grace of Soul, it can be done.

I would like to make a special reference to the Ngannawal and Ngarigo tribes who were the Indigenous inhabitants of the region for more than 20,000 years. In particular, I would like to dedicate this short presentation to a descendant of the Ngannawal people, a very special friend and participant in my Granny Burnout Study, Aunty Marie Bond (nee Moore) who moved to Cherbourg as a young bride until her death from diabetes, heart disease and kidney failure. Aunty Marie and her family have voluntarily contributed much to my work and their stories typify the ongoing, rapidly escalating roller coaster health and social crisis that Australia's most marginalised, the Indigenous population, has to endure.

I had intended to name my presentation "Indigenous Children: Invisible yet visible" but Ross Homel kindly suggested "Invisible yet invincible". He also impressed on me the need to project solutions and reciprocity. I shall try my best but as late as last night, I was still trying to deal with the points I have to get across and how to do it without offending. These I see as the most pressing issues - gaining true equality, the cessation of violating policies and research methodologies and then having to "turn tricks" for essential funding to rectify what others have forced on to us. The latter two points will always continue while Indigenous world views are counted as insignificant within the models and the ethos of the dominant group.

I would like to also point out to you that our numbers here today total 95 key researchers, we have all left other important work to attend, and what we are trying to extricate from the ARC in one year for all of Australia's children, is only a little more than the price recently paid for Don Bradman's cap. The message it sends to me is that we are merely performers in a circus or better still, puppets on very rigid strings.

Indigenous researcher, Dr Bronwyn Fredericks, tells the story of a researcher in the field, complete with clipboard, paper and pen, doing observational study. He had a frog sitting on his head. Curiosity got the better of one of the observed who walked up to the researcher, pointed at the frog and said "What's that?" The frog replied "I don't know. It just started as a pimple on my backside and grew." I therefore need to talk about the ongoing policies and procedures that continue as unwanted growths and actually inflict structural violence on Indigenous people. Ross tells me that structural violence must be intended but I disagree as ignorance is not an acceptable defence.

To demonstrate this stance, it is important to actually point out the shortcomings of traditional epidemiological methods from the perspective of a community researcher. Clinicians and medical researchers have actually assisted the insidious onset of neurodevelopment birth disabilities simply by excluding social determinants from their data collections and working from within their own professional paradigms/silos/diverticulum. For it is these missing data that dictates community functioning.

Despite their data collections, missing worlds and hidden voices remain. The most obvious being disabilities due to several generations of exposure to common teratogens such as tobacco, marijuana and alcohol. Other examples to consider are, how do you measure hopelessness and despair? What about childhood depression and the not so delicate, sometimes hidden and sometimes brazen, but always major determinants, such as child sexual, physical and emotional abuse? What about families who are becoming increasingly illiterate and unable to function at a capacity to access reasonable life chances for their children? These factors are mostly only accidentally revealed.

As an example, look again at the physical disfigurements clone of the child who has had pre-birth exposure to one teratogen, alcohol.

An analysis of hundreds of children with FAS seen by Professor Herman Loser at the University Children's Clinic, Munster, Germany, over a period of 20 years found these problems. There were more on the list but I was unable to fit them on the page. FAS has been completely ignored in Australia until the past year or two. With ears and eyes situated differently on children's heads, how could they? If there is tortuosity of the ocular pathways, small teeth and many other measureable physical differences, might not the auditory canals be distorted? Is it surprising children develop Otitis Media? Why has common sense analyses been ignored? Why are we not doing more to show the teratogenic effects of substance abuse from both maternal and paternal sources? Oddly too, we still have separate "Maternal and child health" initiatives and leave fathers out of the picture as if their sperm did the job but was somehow inert from future influences.

Regardless of being the sickest population group, an appalling system of competing for grant funding is discriminatory, dehumanising and further marginalises - a clear case of *victim heal thyself*. Moreover, communities deserve better than ad hoc programs. Anything less than whole of community, whole of life course will deepen despair and continue to violate.

Likewise to conduct yet more research without intervening would be immoral. How much more funding will be wasted on baseline data collection before remedial initiatives are implemented. We have a baseline and should not wait for further deterioration.

The invisibility of our children can be traced to just one clinician being responsible for identifying a problem and making the diagnosis. Professor Susan Astley from the University of Washington, conducts training of diagnostic teams. Trained over a period of three days, usually involves the above seven professions:

Day 1 - teaches preventing and overcoming secondary disabilities in people with FAS and FAE across the life span

Day 2 - preventing FAS with the Birth to 3 Advocacy Model for working with very high-risk mothers and their families

Day 3 - demonstration of a multidisciplinary FAS Diagnostic clinic and relevance for community interventions, parent advocacy, and prevention

Future initiatives in Indigenous communities must involve the some types of teams to assess the teratogenic effects of alcohol, marijuana, tobacco and solvent while educating communities at the same time, irrespective of the cost to government. I don't want to concentrate on FAS but chose to select it as just one major disturbance that has been ignored until now. Also I am mindful that some people here in attendance may not be aware of the extent of exposure to teratogens in communities, and elsewhere where people are marginalised and unable to cope with the difficulties of life.

The predictions of poor adult health outcomes begin before birth yet we continue to ignore the circumstances into which many Indigenous children are born. Endemic social dysfunction and violence are ignored even though the evidence about risk factors is there. The socially engineered changes from hunter/gatherer to rations, to severe nutritional deprivation, coping with hopelessness by turning to substance abuse, has caused a biological disaster that can truthfully be referred to as biological genocide.

As researchers, we can all take some of the blame for this. And as I stated previously, saving the lives of the nation's most downtrodden should not be dependent on turning tricks for money.

We talk about collecting more data - for what? We write - for whom? Peer review articles for our own progression?

So we need, not just some, but an entire solution package.

Originally, the model shown was developed from the Indigenous Cohort of the Australian Longitudinal Study on Women's Health, now Women's Health Australia. It was designed to allow women's full participation, especially ownership, in research planning, implementation, evaluation and reporting, that is, at every stage of the process.

This model could be easily adapted for every interaction with any population group especially to turn consultations into opportunities and shore reciprocity. It would replace the present modus operandi of community consultations, that is arrive on a given date or call the community into the city for a consultation meeting, what is it you want? For groups who don't have access to research findings, it becomes a tokenistic exercise.

There has to be reciprocity built in and this must involve knowledge sharing so that those consulted are able to locate their realities within documented research studies as shown here in the Women's Learning Circle.

Bear in mind too, that those operating successfully are more heavily burdened with day to day running of facilities so if you are planning to put in interventions, evaluations, etc, you must also be prepared to give a helping hand. This statement always brings the cry "But we don't have the resources or wait until I see if I can get a grant." Our reply should be to the bureaucrats that the child cannot wait.

Our approach has to be radical. We all need to become very active activists and concentrate on the breaches of human rights. Refuse to turn tricks for essential services for disadvantaged children and their families. For Indigenous families, recognition of the extent of destruction created by past experiences needs to be written about. Forget about the peer review articles. Our role should be to educate the politicians and the public, face the initial outcry but truth has to be the winner.

We need to get our priorities right and I ask you to consider the following recommendations.

Number one priority must be the needs of community and this must be firmly stated to governments and other institutions.

Indigenous projects must be regenerative and financially independent of competitive grant schemes. Working with the model above, or a similar one, a blend of evidence based practice, grounded theory and insider knowledge needs to be used to gather an accurate representation of the population and the engines that drive community functioning.

Researchers at all levels of hierarchy must be exposed to direct interactions with the community for a minimum period of one week per year. It would produce hardly plausible output to write about population health and social problems without experiencing firsthand the day to day existence of the group under scrutiny.

Instead of peer review articles firstly, we should be writing papers with and for the community. As Margot Prior demonstrated, approximately a year ago, an article written for *The Australian* financially rewarded those of us who contributed.

If we are fair dinkum about making a difference in the lives of Indigenous children, that must be our commitment. The future of Indigenous people as a race rests upon the shoulders of you all for if we cannot 'grow up our kids better', as is the present situation, our communities will continue to implode and biological genocide will be complete. I repeat Peter Nathanielsz's words *How we are ushered into life determines how we leave*

Further reading

Galtung J, 1990. Cultural violence, *Journal of Peace Research*, vol. 27. no. 3, pp 291-305.