

# Early impressions of paediatric health in Alice Springs: trying to see beyond the gaps

Marcel D Zimmet

*I was asked to review the article below, and found it a compelling read. Zimmet has clearly gone to central Australia with an open heart and mind, and has discovered an intriguing world previously not known to him. He ends his article with a gentle challenge to those of us who have the privilege to work in health care, to consider whether our current methods are best practice, and whether they are best suited to all who seek our help.*

*Having read this article, I found myself with two unanswered questions. First, given that there have now been several generations of Aboriginal people advocating for improvement to the dire circumstances in Aboriginal health, how is it that our young colleagues are still so shocked when they come to our communities? What is it that we (older Aboriginal people) have failed to say to get the attention of our health care providers, and their teachers? Second, how can we see to it that we produce many more graduates of the quality of Zimmet, who see the world with fresh eyes, are not afraid to ask the obvious questions, and are bold enough to tell us all that the Emperor is indeed naked?*

*I strongly recommend that Journal readers take the time to read this article, and spend a moment or two in reflection to examine their own souls, to see if they can rise to this young man's challenge.*

*Louis G Peachey, BMed, FACRRM, Foundation President, Australian Indigenous Doctors Association, Canberra, ACT.*

In the Alice Springs paediatric ward, the vast majority of the 20 or so children are Aboriginal. They often have unique first names with an African-American or biblical flavour and distinctive spellings. Some come from town, while others travel from hundreds of kilometres away. Parents often lie with their children on mattresses on the floor, watching Disney DVDs, drawing, and waiting for the sporadic visits of hospital staff.

For families, a visit to the ward can mean a period of isolation from their community or time with relatives who live in Alice Springs or who also happen to be in the hospital. It may be an unwanted upheaval from relatively peaceful community life, or an urgent and welcome respite from upheavals at home.

What distinguishes the Alice Springs ward most is the type and severity of paediatric health issues. There is a whole other spectrum of health and disease in central Australia — one that challenges the heart and the mind.

## Labels that don't stick

The categorisations of disease as I knew them after several years working in Melbourne seemed to collapse when I arrived in Alice Springs. Trying to apply learnt diagnostic and management techniques proved futile in the face of the ostensibly distinct nature of “common” illnesses like gastroenteritis, pneumonia and ear infections in central Australian children, let alone their coexistence with nutritional, social, cultural and historical factors.

It is not uncommon to see 4-month-old infants with perforated ear drums. In contrast to coastal city paediatrics, “pink” or “red” tympanic membranes suggesting otitis media do not show up as threats on the diagnostic radar. Ear examination in central Australia is focused on detecting the presence or absence of pus or perforation of the tympanic membrane. Anything less is considered “healthy”.

A child presenting with “gastroenteritis” can mean anything from a prolonged cryptosporidium infection to multiple parasitic and worm infestations. Families often refer to these different ailments generically as “guts ache”. Treatment ranges from frequent correction of significant acidoses and hypokalaemia, to using nitazoxanide to treat cryptosporidium. This drug is only available on the special access

scheme in Australia, not because it is unsafe, but because so few children need it. The evidence for its use, however, is limited to a few studies, mainly in settings somewhat different to Alice Springs. This is a recurring theme in paediatric medicine here — that evidence from either “first-world” metropolitan research centres or the “third-world” does not necessarily translate to what health workers see in central Australia, a “fourth-world” inside our country.

Further, century-old pathological definitions that define disease rather than causation or environmental and social contributors often do not provide us with adequate solutions today. They help us to heal the surface of the skin or lungs, perhaps the lining of the gut, but not always the deeper tissues.

The tragically prevalent conditions of chronic suppurative otitis media and chronic suppurative lung disease in children could perhaps be more accurately defined as “chronic exposure to over-crowding, tobacco smoke, inadequate nutrition and bacterial respiratory tract colonisation”. Similarly “failure to thrive” might often be described as “failures of family and community structures, supports and function”.

## Effects on causes

As paediatric doctors at the hospital, we work closely with families, Aboriginal liaison officers, community organisations and even traditional healers. However, I feel we see the causative cycles of the social determinants of Aboriginal child health, yet cannot always avert the outcomes. Just like someone watching the desert heat evaporate the land's water over several days, I often feel incapable of doing more than merely waiting for the storm to arrive.

Chronic ear infections cause endemic conductive hearing loss. The result for many children is developmental, learning and behavioural issues with profound ramifications for schooling, employment prospects, parenting capabilities, their own future children and their communities.

We try to encourage and empower adults to mop their children's suppurating ears regularly to facilitate healing and help antimicrobial ear drops reach the middle ear, but, often, we don't properly explain why this is important, or there are no tissues available at home, no



refrigerator to safely store the antibiotics, or more urgent daily issues arise.

The daunting challenges of social disadvantage, disharmony, and physical distance can cause health practitioners to minimise our efforts. Sometimes optimum care is not provided on the basis of assumptions about what families will do when they leave. Rationalisations such as “they are not going to give the medication so why bother” or “they’ll be back with the same problem in a week” are sometimes heard. This can be a result of us not being able to see the children and families we look after in the foreground, with their own unique strengths and weaknesses, existing within and beyond these pervasive problems.

### Seeing difference, seeing ways through the gaps

Our lack of flexibility and our inability to — accommodate difference can potentially perpetuate the health gaps. There are many situations in which the pressures of the ward have limited my time to be patient with a family, listen carefully, or negotiate a treatment plan meaningfully, in order to understand the family’s perspective better and expedite the child’s recovery.

I have also found it extremely important always to look for differences between individual Aboriginal children and families to prevent comical gaffes, therapeutic disasters and the spectre of racism. Aboriginality is not homogenous. Alice Springs and central Australian people have a complexity that is at odds with the predictability of the desert heat.

If we accept that a fundamental component of racism is generalisation, then we are all caught in its web more than we would like to admit. This can be as simple as me assuming that a very dark skinned Aboriginal mother could speak an Indigenous language, or that her English would be limited. Neither was true and she spent much time articulating her worries about breastfeeding.

Language difficulties play a major role in paediatric health gaps in central Australia. So much still seems to be “lost in translation” in the gap between English and the multitude of local Aboriginal languages, and between differing understandings of symptom durations, rationales for treatment and discharge plans. Translators are not available after hours, when clarity is often critical.

There are other dimensions. There are well known and beautiful places near and around Alice Springs called “gaps”, where the mountain ranges part to reveal waterholes and jagged red rock facades. These geographical gaps were given names like Heavitree Gap or Emily’s Gap by Anglo-European explorers. They are important dreaming sites for the local Arrernte people. Heavitree Gap is a place where the local traditional owners would formally welcome and accept visiting people onto their lands. For Arrernte people then, talk of closing “gaps”, may have very different meanings from our own.

Dr Patricia Miller, a senior Arrernte woman, recalls another elder fearing that someone would literally close Heavitree Gap, thereby preventing people and transport from entering Alice Springs directly. She could not understand why there not been meetings to explain the closure of such a significant cultural place.

“Closing the gap” can also have an array of ramifications for different families. For some, it may mean having to bring their children to clinics for a seemingly endless array of needles, whether for vaccinations, antibiotics or iron supplementation. For others, it is about not having to tell three or four different doctors in one day what has happened to their child after being transferred from a remote area, or not having to explain the same thing repeatedly because community and hospital information systems are in silos. For some Aboriginal

people, “closing the gap” may mean doctors learning to “speak” to each other better.

For one family, “closing the gap” is a hope for a larger home in which 20 people do not have to share two bedrooms, so their child can get some sleep away from noisy adults. For another family living in town, it may be that “closing the gap” means not having their child’s Aboriginal status questioned because of his or her lighter skin colour and mixed descent.

### Looking and listening

Some of the health gaps and misunderstandings in health care also relate to how, for many Aboriginal people, conceptions of space and time are significantly different to medical thought. The chain of cause and effect, and the ideas that illnesses have names, time courses and scientific reasons for appearing are often not the main paradigms for our patients in central Australia.

A grandmother explained to me, with the assistance of an Aboriginal liaison officer, that the reason why her 18-month-old granddaughter was not eating or growing properly was not because she was still breastfed by her mother and had trouble eating solids, but because the unborn baby her mother was carrying was playing tricks and interfering with its sibling’s eating habits.

A few mothers on the ward told me about the changing winds and misplaced internal rocks that had ravaged their children’s bodies. They had taken their children to see the traditional healers before seeing a doctor. One mother, a painter and former Aboriginal liaison officer, told me she struggled with prioritising one form of healing over the other.

This mother and her child are just one example of the astounding resilience of children and families in central Australia. Their ability to remain healthy, keep a sense of humour, stay positive and return to the hospital or clinic for a visit is remarkable. It is even more extraordinary considering the harsh environment and limited resources. This resilience needs to be supported and harnessed at all costs. It is critical that we strengthen Aboriginal families by using their unique structures, dynamics, hopes and needs.

The challenge, then, is to balance a paediatric perspective with an Aboriginal one. The two are not mutually exclusive. We have to keep our paediatric medical gaze sharp and unprejudiced. An evidence base should be built for treating the unique conditions that are seen in central Australian children. Concurrently, ensuring that national standards of nutritional and child development health are implemented in the region is paramount, as a matter of health equity and human rights. We need to make sure that what we know as “truth” in paediatric medicine is applied equally to children living in remote areas and, at the same time, keep our eyes, ears and hearts open to the varying strengths and needs of each child, carer, family or community. We should listen to what they tell us and be comfortable with the silences.

We need to find ways through the gaps from several vantage points, with Aboriginal people leading the way back to their own health.

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