

Coalition for Research to Improve Aboriginal Health

***3rd Aboriginal Health
Research Conference***

**Keynote Address:
*Research for a better future***

By

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Abstract

The last twenty years has seen great changes in the field of Aboriginal health research.

Research based on collaboration with the Aboriginal community and its organisations is now best practice. Research is no longer simply accepted as something done 'to' Aboriginal communities; now it is done 'with' us and increasingly 'by' us.

Despite these positive changes, much remains to be done.

Public policy in Aboriginal health continues to be driven by other, often unstated, assumptions and agendas.

The great challenge for the future of Aboriginal health research is the need to ensure that public policy is based on sound evidence, and on what we already know will lead to healthier, happier communities.

Good morning brothers and sisters, ladies and gentlemen

I acknowledge and pay respects to the traditional custodians of the land on which we are meeting today.

It is a pleasure to have been asked to address you this morning.

I have been asked to share my thoughts on the theme of this conference: 'research for a better future'.

And I will certainly get to talking about the future, but I will start by talking about the past.

I would like to share with you some reflections on the changing face of Aboriginal health research over the last twenty years or so, and to provide some personal answers to the question of how we come to be where we are today.

I think this recent past demonstrates a real change in how research into Aboriginal health is carried out.

This change has helped drive a corresponding shift in Aboriginal community attitudes to research.

However, despite these successes there is one important area where so far little has changed.

That area is so-called ‘evidence-based public policy’.

As an example, I would like to look at a particular current policy with which we are all familiar – the continuing ‘Intervention’ in the Northern Territory.

I would like to share with you my thoughts on how this came into being, and reflect on the role of evidence and research – or rather the lack of it – in this dramatic re-shaping of the relationship between the Australia’s First Peoples and the Australian nation-state.

I will argue that the Intervention points to the need for a fundamental re-setting of the relationship between black and white Australia.

I will leave you with what I see as the great challenge for the future of Aboriginal health research – the need to ensure that public policy is based on sound evidence, and on what we already know will lead to healthier, happier communities.

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If I look at the program for this conference, and if I look at those attending here today, I see something I would not have

seen twenty years ago: to put it bluntly and a little crudely, I see a lot of black faces.

It is also clear from the conference program that much of the research being shared and discussed over these two days is created, designed and run in partnership with Aboriginal communities.

These two changes – in the numbers of Aboriginal researchers, and the way we carry out research – tell me that a great deal has been achieved in recent years.

Many organisations and many individuals (Aboriginal and non-Aboriginal) have been responsible for these achievements and they all have their story to tell.

Today, I 'd like to start by sharing my experience during that process of change.

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In the 1980s, 'research' was still a dirty word for Aboriginal people.

Decades of research carried out by non-Aboriginal researchers, based in non-Aboriginal institutions, had left many of us deeply suspicious of the 'R' word.

We had won rights in many areas of their lives, and we had established a network of community controlled health services across the country.

But when it came to research we were still continually being asked to participate in other people's processes that served other people's priorities.

The research agenda was set in forums to which few of us had access.

There were few Aboriginal researchers.

And research methodology was still focussed on Aboriginal people as subjects of research: research was something carried out 'on' us as Aboriginal people, not 'with' us, and certainly not 'by' us.

Worse still, despite the large volumes of research to which we were subjected, very little seemed to be translated into practice: the research projects came and went, but health service delivery and policy remained the same.

Of course, there were always those researchers who developed good relationships with communities and did their best to make the results of their research known and useful to people and organisations on the ground.

But they were the exception rather than the rule.

Consequently, if anyone proposed health research, our people, communities and organisations would be cautious (to say the least) about participating.

It was in this atmosphere that I was working as the CEO of an Aboriginal Medical Service in the Northern Territory in the early 1990s.

And it was around that time that some of us in the Aboriginal health sector began to think about how research could be made more useful and appropriate for our communities.

We started to talk about how – rather than spending so much energy trying to ‘keep the researchers out’ – we ourselves could ‘get in’ to the research world and help shape it to better meet the health needs of Aboriginal people and communities.

We began to think about what research from our perspective would look like: research based on our experience of our

communities, of service delivery in these places, and of the effects of government policy that was constantly changing without any reference to us.

There were two important events that contributed to this change in our thinking.

The first was the emergence at around this time of the theory of the social determinants of health.

As we all know, this theory simply states that the health of peoples is not just about health services.

Access to appropriate health care is of course an important determinant of health.

But health is also strongly influenced by a range of social factors – poverty, employment, education, access to food and transport, housing, stress and social exclusion or racism.

This idea is now almost universally accepted amongst researchers, policy makers and service deliverers in Aboriginal health.

But in the early 1990s it was relatively new as an academic theory.

What struck us, though, was how closely it matched what many Aboriginal activists and communities had been arguing for a long time.

For example, the definition of health put forward in the landmark 1989 National Aboriginal Health Strategy put it simply and well:

[quote]

[Health is] not just the physical well-being of an individual but the social, emotional and cultural well-being of the whole community ...

[unquote]

And, although they put it so beautifully, the National Aboriginal Health Strategy Working Party did not invent this holistic Aboriginal definition of health.

The political struggles for Aboriginal rights of the 1960s and 1970s had the same idea, under the label of what we then called the “underlying causes of ill health”.

Land rights, access to quality education, freedom from discrimination and racism, self-determination: all these were

explicitly part of the movement with which we sought to achieve better health for our peoples.

For us, the idea that poor health was linked to broader social and economic issues was also reinforced for us every day by our lived experience.

We could see in our own communities and our own families the effects of poor housing, unemployment, racism, and the day-to-day stress of worrying about where the money was going to come from for this week's rent or for the kid's clothes.

We could see that this was how the world worked, in a way that was probably not so obvious to those from more privileged backgrounds.

So, when the theory of the social determinants of health appeared out of academia, telling us that it had now been "proved" that social, emotional and political issues affected our health, it aroused mixed feelings amongst many of us.

There was a temptation to put our hands on our hips, sigh loudly, and say "Yeah, that's what we've been trying to tell you for the last two hundred years!"

However, that aside, the theory was welcome as a confirmation of our experience and of the “holistic” approach to Aboriginal health we had been living and advocating.

It provided a powerful new way of conducting the argument about how to improve the health of our communities.

We could see immediately that the ‘scientific’ nature of the evidence was much more difficult for politicians and policy makers to deny than our arguments from political analysis and community experience.

So this new theory was significant in helping to build a bridge between the research community and the Aboriginal community sector.

This, we could see, was the kind of research which could help solve the problems our communities were living.

This was a research agenda which we could relate to and which we felt had something to offer to our health services and our communities.

So we began to develop contact with researchers interested in this “social determinants” approach.

They became our “way in” to the research world – the door was opened, if you like.

The second key event – the one that allowed us to walk through that door – was the establishment of the Cooperative Research Centre Program by the Australian Government in 1990.

This program had the aim of bringing together research institutions with those organisations who use research outcomes, to develop user-driven, cooperative research with a focus on practical outcomes.

The door was open, but it was Professor John Matthews, then head of the Menzies School for Health Research in Darwin who tried to get us through that doorway, by suggesting a joint application to the CRC Program.

We, in the community controlled health service sector in the Northern Territory, were very cautious.

Along with our growing realisation that we needed to be more part of this research world, we also wanted to design, manage and control the research agenda itself.

This seemed a big task, and many in our sector remained deeply suspicious of the research world.

But finally John's persuasiveness, aided and abetted by Professor Marcia Langton, paid off and we decided to come on board, to take up the opportunity and be part of deciding and implementing a research agenda which met our needs.

After much discussion and negotiation, a collaboration of six partners (Flinders University, Northern Territory University, Northern Territory Health Services, Central Australian Aboriginal Congress, Danila Dilba Aboriginal Health Service, and Menzies School of Health Research) put together a proposal for a Cooperative Research Centre for Aboriginal and Tropical Health.

In July 1997, the bid was successful and the new CRC was established to undertake research and education activities that would lead to better outcomes in Aboriginal and tropical health.

I have to say that the marriage between the Aboriginal community health service world and the research world was at first an uneasy one.

It was a difficult learning process us as Aboriginal people and as leaders, as well as for all our partners and for researchers themselves.

I think it's worth reflecting for a moment on what made this relationship so hard.

Certainly all partners and participants were committed to making it work, so lack of good will certainly wasn't an issue.

Nor was inexperience: obviously those from the research institutes were senior people with long and in many cases internationally recognised careers.

And those of us from the Aboriginal health services were hardly babes in the woods either.

All of us were running multi-million dollar health services, and were just as comfortable treading the corridors of power in Canberra as we were negotiating the complex networks of relationships in the Aboriginal world.

We also had long experience relating to individual researchers and research projects.

But for us – for me at least – it was like discovering that the researchers were only the tip of the iceberg and that behind them there was a whole landscape of relationships and ways to do things, a secret and often alien world.

In this world, the language was different, the manners were different, the processes seemed complex and cumbersome (even for us from the world of the Aboriginal Medical Services, where extensive reporting and accountability processes were part of our everyday work).

No doubt those from the research world found our ways that we brought from service-delivery-land equally strange and difficult.

What I am trying to convey is that, on a very personal level, I found that the worlds of research and of the Aboriginal community organisations are not an easy fit.

I suspect that this is just as true now as it was back then.

Perhaps on both sides we have got better at managing the relationship – but I think it is a lesson worth remembering: despite its importance, the relationship between the Aboriginal world and the research world is not a natural or easy one –

and to make it work requires commitment and effort, as well as tolerance, trust and acceptance.

Very fortunately for us all, the Chair of that first CRC Board was Lowitja O'Donoghue.

She brought her considerable experience and skills to the job, as well as her well-recognised qualities of toughness and fairness.

She made us put aside our suspicions and misgivings and to get on with business.

Gradually, under her leadership, a sense of partnership and collaboration grew, along with a new approach to research.

This new way put issues of Aboriginal empowerment and knowledge transfer at the centre of the research task.

The focus was on research that would make a difference and improve Aboriginal health, but throughout there was a strong emphasis on Aboriginal control of the research agenda, as well as research processes.

Knowledge transfer – how to transfer knowledge into practice – was central to our approach, as was increasing capacity in the Aboriginal community through education and training.

As it developed this new way, the CRC developed into a good place for non-Aboriginal researchers to work as well.

They learnt new skills and new ways of conducting research and they developed relationships with Aboriginal communities and community-controlled organisations that may have been much more difficult with old researcher-driven approach.

This new way was a success.

At the end of the first funding cycle in 2003, an expanded CRC partnership was funded by the Australian Government.

And in 2010, we were funded for a further five years – leading to the recent establishment of the Lowitja Institute, Australia's first permanent body for collaborative Aboriginal health research in the Australian research landscape.

Throughout, we continued the principles of Aboriginal participation and control; inclusive approaches to health research; the transfer of research into practice; and the

provision of research and training opportunities for Aboriginal people.

These have become acknowledged as 'best practice' in Aboriginal health research.

I believe the various iterations of the CRC have helped change attitudes in the research world to why, how, where, and by whom research is carried out.

I also believe we have helped lead a shift in Aboriginal attitudes to research.

While some Aboriginal people, organisations and communities retain an scepticism about the benefits of research, the widespread hostility of the past is largely gone.

Critical to our ability to lead change has been what I regard as our greatest success – the building of research capacity within the Aboriginal community.

These collaborative organisations supported, trained, educated and employed hundreds of Aboriginal students and researchers and they are, I believe, our most important and enduring legacy.

This brings me back to the here and now.

Looking back, I hope I have given a sense of the challenges and difficulties that have gone along with the processes which have transformed Aboriginal health research.

Many of you took that journey with us – either through an association with one of the CRCs or through many of the other organisations and processes that have contributed to that transformation.

Despite these positive changes, there is always more work to do to ensure health research is a collaborative and practical process, that empowers Aboriginal people while contributing to better health for our communities.

That is why I believe the establishment of the Lowitja Institute late last year is critical for the future.

The Institute is named, of course, after our first CRC Board Chairperson and internationally recognised advocate for the rights of our peoples, Dr Lowitja O'Donoghue.

The Lowitja Institute, by being a permanent institute for Aboriginal health research, means that the lessons and the processes established under the CRCs since 1997 will not end

when the Cooperative Research Centre program funding finishes in 2014.

So, I would urge support of the Institute, of which (as you know) I am Chairperson.

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Which brings me to the big question about the future of Aboriginal health research in Australia.

What are the priorities?

In my mind, without question, the biggest and most important priority is this: ensuring that public-policy is based on what we know works.

In short, we need to make ‘evidence-based policy’ a reality, and not just an empty phrase.

You would think that the idea that government policy be based on good evidence would be (as the Americans might say) a “no brainer”: so obvious as to not require debate.

Unfortunately, when it comes to policy on Aboriginal health – or Aboriginal anything – in Australia, this does not appear to be the case.

Instead, all sorts of other factors seem to take their place ahead of the evidence when it comes to making the ‘big’ decisions on Aboriginal health and well-being.

These other factors may include calculations about narrow political advantage, unexamined prejudices and assumptions, even sheer personal ego.

Overwhelmingly, they remain hidden.

Let me take, as an example, the most profound change in Government policy designed to affect the health of Aboriginal communities in recent decades – the Northern Territory Intervention.

As many of you will know, in 2006 I was asked by the Northern Territory Government to carry out – along with Rex Wild QC – an inquiry into child sexual abuse and neglect in the Territory.

This followed disturbing – though I am sorry to say, not new – revelations about the way children were being maltreated and neglected in Aboriginal communities in the Territory.

In looking at this difficult area, our approach was based on two sources of evidence.

First, we wanted to look at the formal published evidence about what works in these kind of situations – we had experts in this field on our team and we spoke to many more during the course of our investigation.

Second, we wanted the evidence and experience of Aboriginal communities and organisations – what they felt, what they believed, what they thought would work ‘on the ground’.

So, over the course of a year, Rex and I travelled to over 40 Aboriginal communities around the Territory and held extensive community meetings to get Aboriginal people’s views on how to ensure that their children grow up safe, healthy and ready to be part of their community and the nation.

We held full-scale community meetings, as well as separate men’s and women’s forums, and meetings with individuals and service providers.

What struck me most from these consultations was the attitude of those who spoke with us.

They had suffered much as a result of the historical processes in this country, and many had suffered violence and abuse themselves.

Many were sad, distressed and shamed by what was happening in their communities and in their families.

But they were owning the problem, they were not turning away and saying it was too hard.

They wanted to work with the professionals, they wanted to work with the government and with the service delivery organisations: they wanted to be part of the solution.

And they were open to ideas and evidence from elsewhere that might help their own communities.

When Rex Wild and I came to write the report, we recorded as faithfully as we could what people told us, and we put forward almost one hundred recommendations to address the issues they raised.

These recommendations covered a whole range of areas – child protection services, health services, policing, rehabilitation, prevention, family support, education, housing, alcohol, employment, and more.

But for me the very first recommendation was the most significant. It said:

It is critical that both [the Northern Territory and Federal] governments commit to genuine consultation with Aboriginal people in designing initiatives for Aboriginal communities [to address child sexual abuse and neglect].

This recommendation was strongly informed by the willingness and determination of many in the Aboriginal community to work with the authorities to address the problems they faced.

It was also strongly based on the evidence.

We know that the evidence on the social determinants of health includes confirmation that ‘the control factor’ – what we might call empowerment – is a critical determinant of health.

Conversely, disempowerment and social exclusion have powerful negative effects on health.

Practically, this means that any policy aimed at reducing the disadvantage of our communities must from its conception through to its implementation and beyond, ask itself how it will increase the ability of Aboriginal people, families and communities to take control over their own lives.

This is clearly not a matter of a ‘hands-off’ approach that just leaves Aboriginal communities to their own devices.

Our recommendations were premised on the idea that many of these communities needed substantial assistance and support.

However, in keeping with the evidence (and, I might add, various international conventions to which Australia is a signatory) our report recommended an approach where the support is delivered with and in consultation with communities, rather than imposed upon them.

So ... we delivered the *Little Children are Sacred* report to the Northern Territory Government in April 2007.

For a while there was silence; and then in June 2007, the then Prime Minister and his Federal Minister for Indigenous Affairs announced the ‘emergency intervention’ into the Northern Territory.

There were many elements of the Intervention announced that day.

Not all of these were wide of the mark: there were moves to restrict alcohol availability, enforce school attendance, increase policing, and ban pornography.

However, no one needed an inquiry to tell them that these measures were needed – there had been broad agreement for a long time about exactly these kind of actions.

Critically, however, our recommendation about working with Aboriginal communities was ignored.

Where we emphasised the need for resources and for flexible processes of engagement with Aboriginal families and communities, the Intervention emphasised external control and ‘blanket’ provisions affecting all Aboriginal people.

The majority, and the ‘headline’ elements, of the Intervention, were deeply problematic.

They included compulsory health checks of Aboriginal children to check for evidence of abuse, blanket quarantining of welfare payments to all Aboriginal people (leading to the suspension of the *Racial Discrimination Act*), the compulsory acquisition of Aboriginal townships, and the scrapping of the permit system that allowed Aboriginal people control over access to their land.

These proposals were accompanied by a ‘get tough, quick fix’ rhetoric that made it abundantly clear where the problem lay:

it lay with us, it was Aboriginal people who were to blame for the conditions in which we lived.

What we needed was a good kick up the bum, and then the non-Aboriginal State would just have to come in and fix it all for us, as we were obviously incapable of doing so ourselves.

So, where was the evidence-base for this radical re-shaping of policy, for this return to a paternalistic approach to problem-solving?

Simply: it was absent.

There was no attempt to justify the policy by reference to evidence.

There was no attempt to address the fact that the vast majority of the evidence pointed in exactly the opposite direction to where the policy was going, towards approaches based on empowerment and inclusion rather than imposed solutions and paternalism.

There was no recognition of what had been achieved in some places, or of a history of attempts by Aboriginal people and organisations to tackle the complex health and social issues in their communities.

So, if it was not the evidence, what did the former Government base its policy on?

I don't think we'll ever fully understand the process by which the Government decided on the Intervention: the key decisions were taken behind closed doors, and little effort has gone into uncovering exactly how they were made and who made them.

There was, on the other hand, lots of speculation about 'why' the Intervention was announced.

For some, the Intervention was a cynical political exercise to 'wedge' the opposition Labor Party and gain narrow political advantage in an election year.

Others have seen the Intervention as an ideologically driven attack on Aboriginal rights.

Under this scenario, the NT Government's inaction gave Prime Minister Howard the opportunity to further advance his agenda in Indigenous Affairs, central to which was the undermining of Aboriginal rights, especially to land.

Some even saw the Intervention as a genuine attempt to address the suffering and neglect of Aboriginal children.

If so, it was an attempt based on ignorance and almost inevitably, prejudice.

But whatever the real motivations behind the Intervention, one thing I know for sure: it was not concern for the welfare of Aboriginal children and communities that drove it.

And it was not undertaken with a knowledge and respect for the evidence.

And this seems to me to be a continuing theme in the history of the relationship between black and white in Australia: that action on Aboriginal disadvantage gets continually caught up in other, contradictory agendas.

This perhaps has been the biggest barrier to genuine progress.

Because, you would think that if Government was really serious about addressing the disadvantage so many Aboriginal communities suffer, there would be a rational process.

They'd sit down and look at what the problems were, look at what has already been tried and what we know works, look at the kind of principles that we know should underpin action – and then, a make a commitment to action and of resources.

Yet as far as we know, the whole Intervention was almost literally designed on the back of an envelope, over two or three days, in some offices in Canberra, by people who took little account of the evidence, and had no understanding of the historical realities of Aboriginal life.

Now some people have said to me: “But something had to be done!”

Of course, I agree: “something” had to be done.

But if you are seriously ill in hospital and “something has to be done” you expect the “something” that the hospital staff do to be both aimed at treating the illness, and to be based on good evidence.

Doing something that is neither well-intentioned nor well-evidenced is unlikely to be helpful.

And in my view the Intervention was neither well-intentioned nor well-evidenced.

Following their election victory a few months after the announcement of the Intervention, the Federal Labor Government withdrew some of the more controversial measures.

It has softened the rhetoric somewhat.

But the essential structures and the thinking of the Intervention remain in place.

Explicitly or implicitly, it rejects self-determination as a 'failed policy'.

It does not approach our communities as having anything valuable to offer or indeed of having achieved anything in the past.

Instead, they are to be the passive recipients of non-Aboriginal "help".

This has left many Aboriginal people marginalized from the decision-making processes in their own communities.

It adds to the sense of disempowerment and stress that many already feel.

And we know that this diminished sense of control and increased stress will lead to poorer health and social outcomes in the future.

In this way, the future of Aboriginal children in the Northern Territory is not being protected by the Intervention: it is being further undermined.

...

So to conclude with the question at the heart of this Conference: how can research contribute to a better future in Aboriginal health?

First, we have to ensure that research is something done with and by our people, not on them.

As I have described this morning, I believe we've made a lot of progress in this area over the last twenty years, and I think that this progress is something that both the Aboriginal community and the research world can celebrate.

Second, I believe that, we all have a responsibility for helping to ensure that the policy decisions which are going to have an effect on the health and well-being of Aboriginal communities are based on good evidence.

We need to participate and encourage debate that is informed by what we know: as researchers and as members of the Aboriginal community.

We need to encourage genuine dialogue, that respects the experience and achievements of our peoples.

This is complex, and it is difficult.

But in my view it means that all of us have the responsibility to ensure that when it comes to the health and well-being of Aboriginal Australia, public policy must be based on good evidence.

We have a responsibility to ensure that, as a nation, we get beyond the 'we know best' attitudes that so often set policy directions, while in reality, it is other unspoken and even unconscious agendas which are determining the direction we are all expected to go.

This is the great challenge for the future of Aboriginal health research – making sure that public policy is based on sound evidence, and on what we already know will lead to healthier, happier communities.

Thank you.