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The Health Report: 7 November 2005 – Aboriginal Health

Norman Swan: Welcome to the program. This morning on The Health Report a unique study of Aboriginal child and adolescent health which has messages for us all and explodes a few myths along the way. Plus a tale of spectacular success and tragic failure which shows how the system can get it wrong when it comes to providing medical care for Aboriginal people and Torres Strait islanders.

The study shows what a difference can be made and how bureaucracies can stuff things up. The setting is the Northern Territory and one of the people involved was Wendy Hoy, who's now Professor of Medicine at the University of Queensland.

Wendy Hoy: Aboriginal people across Australia have about as threefold increase in deaths and a tenfold increase in kidney failure but rates are much higher in some remote regions. And much of this is due to chronic diseases like high blood pressure and kidney disease, diabetes, and cardiovascular disease. And we know from experience in the non-indigenous population that standard treatments can dramatically reduce progression of all these conditions.

Norman Swan: So simply treating blood pressure, treating high cholesterol that sort of thing?

Wendy Hoy: Yes indeed. Now the community described in this has the highest rates of kidney failure in the world and a sixfold increase in rates of adult death and our earlier work there showed that systematic testing and treatment of people with high blood pressure and kidney disease dramatically improved blood pressure and resulted in a 50% reduction of deaths. And the numbers of people starting dialysis for kidney failure fell by two thirds and there were huge cost savings.

Norman Swan: And how were you doing that?

Wendy Hoy: Just by regularly testing people for hypertension and kidney disease and putting them on the appropriate medicine and following their course.

Norman Swan: And doing that as a sort of shock team or through an Aboriginal controlled medical service.

Wendy Hoy: A nurse practitioner visited from Darwin a few days a week and we used a team of community liaison people from that community itself as on

site health managers. I supervised the introduction of treatment largely remotely from Darwin.

Norman Swan: But things didn't go well forever though did it?

Wendy Hoy: Oh indeed not. In 1999 we began a process of handing the responsibility for the program over to the newly constituted community health board which was given the responsibility for managing the primary care services of their community through the recently introduced co-ordinated care trial model.

Norman Swan: And was this what people call a community controlled health organisation in Aboriginal terms?

Wendy Hoy: Conceptually yes. In real practice there was a fair bit of influence and input as there needed to be from government health agencies. Community people who didn't necessarily have any particular health expertise were invited to join the board and were given the responsibility of running their primary health care programs which is extraordinary really, given that you know these are the sickest people in Australia and would be a challenge in any primary health care model.

Norman Swan: What happened?

Wendy Hoy: After a hand over to the health board gradually the intensity of the program was relaxed. Regular testing of people for early disease fell off and many people who were already on treatment stopped taking their medicines. Blood pressures went up and within a year or two rates of kidney failure and other natural deaths were back to higher than rates before the treatment program began. Thus here's the story – excellent results were achieved by good management and they were lost when intensity of management was relaxed.

The issue of why the health board failed is a problematic one. I wasn't involved with the constitution of the board or management of its affairs so I can't comment accurately.

Norman Swan: And co-ordinated care trials, I don't want to get too bureaucratic here, but this was a process really started by the Commonwealth to try and get linked care so you didn't get fragmentation in the health system so that the right hand knew what the left hand was doing in a sense.

Wendy Hoy: Yes that was the intent.

Norman Swan: But what you're describing here is a spectacular failure of it.

Wendy Hoy: Well indeed, the board experienced some difficulties and incurred a cost over run. They felt that they were unfunded relative to their actual as opposed to their estimate client base. And when things began to get tight the chronic disease program was one of the activities to suffer.

Norman Swan: Even though your program was primarily run by local people

with a fairly light touch by you at a distance it fell apart?

Wendy Hoy: No touch by me at a distance any more. The supervision of the program no longer rested with us.

Norman Swan: And why was that?

Wendy Hoy: Northern Territory government health service had taken over the advisory role for the health board in all matters of their primary care.

Norman Swan: So what you're saying is that the commitment to the program diminished?

Wendy Hoy: That's exactly right and ultimately they were disbanded and went into receivership. But let me say whatever the ingredients of their problems the board was not baled out of their financial difficulties nor were they given constructive direction and support. And this is really sad given that this was an experimental undertaking and given that regional hospitals are routinely, and I might say appropriately, forgiven cost over runs that are orders of magnitude bigger than this.

Norman Swan: So this Aboriginal community was hung out to dry?

Wendy Hoy: Well those are your words Norman, I think that the co-ordinated care trial project was not constructed to be flexible enough to respond to the lessons that would necessarily be learned while it was being conducted.

Norman Swan: And what's the situation now?

Wendy Hoy: In response to my description of the events following the down regulation of the chronic disease activity there was extra staffing and especially more doctor staffing appointed and that activities increased. But sadly this has been short lived and there's now not one resident doctor on these islands despite a population of perhaps up to 2400 people and those being the sickest ones in Australia. So we're back to a status quo that is really pretty sad.

Norman Swan: Presumably it's hard to blame one person for this, it's the system has utterly failed.

Wendy Hoy: Exactly and look I've inferred that this is part of a bigger story and this rests in the chaotic and under-resourced nature of primary care services for Aboriginal people across Australia. There's a total lack of coherent planning across the nation, a total lack of accountability for quality care for clinical outcomes or for spending. And it's really remarkable that this persists in a country that successfully deals with other health threats and where the target population is so small. And we have to ask ourselves why – are we as health care providers or researchers and policy makers failing to make a clear case to government or are they failing to respond.

Norman Swan: How can we do it better?

Wendy Hoy: Government needs to handle this like any other major health

threat, it needs to grasp the problem, it needs to understand its solutions, it needs to adopt over arching strategies, introduce systems of tracking and accountability and adapt the models they develop according to experience and they have to resource them adequately. I feel it must find the modest amount of money that's needed to fix this situation just as public opinion has enabled Queensland to find the dollars to fix Queensland Health. And I truly believe we can convert this situation from a disaster to a success story that we can be proud of. We must have targets for process indicators, we must have targets for outcome, we must have targets for spending. Of course we may not meet those targets or we may decide that the targets needed to be adapted but it gives us a framework in which we need to move forward. And of course there are difficulties, there are in all major health challenges. We need to grapple with these difficulties with an expert panel and work out solutions to them and proceed towards them.

Norman Swan: Now you're white, you're not Aboriginal?

Wendy Hoy: No, I am white.

Norman Swan: And the agenda nationally is Aboriginal community control of these services or Torres Strait Islanders control of these services. How does this fit into even what Pearson's talking about which is communities taking responsibility for themselves?

Wendy Hoy: First of all I don't think it requires such a committee to be manned by a multitude of expert specialists be they white or not. These are really issues of practical and systematic approaches to primary care. There are some marvellously qualified indigenous health practitioners who could assume leadership of such an organisation.

Norman Swan: And just finally what you're talking about here is what people call secondary prevention where you've already got a problem and you're trying to stop that problem getting worse. Where does stopping the problem of kidney disease and heart disease occurring in the first place, what's called primary prevention fit into all this?

Wendy Hoy: Well it's terribly important of course. A multitude of factors feed into this and when they act in concert my opinion is that they multiply risk and our models have shown that rather than acting in an additive fashion. And much of this risk is established in early life or preconception and this early life risk factor status is established with babies with insufficient organ development to carry them through a normal lifespan. And therefore I think intra-uterine and growth and infant health critically have to be improved. And this means improvement in weights of potential mothers, reduction in maternal smoking which is critical, and maternal drinking, avoidance of malnutrition and anaemia when pregnant and reducing infections and sociological stress.

Now it goes without saying that housing and nutrition and recreational and employment opportunities have to be improved drastically. Also critical is improvement in education as the public health literature shows that the health of a child is directly correlated with the level of education of its mother. Finally one of the relatively overlooked factors is there's a really critical need for culturally

appropriate and effective campaigns to reduce smoking. In some communities between 70% and 80% of people smoke and up to 60% or more are pregnant mothers. Now this is about three to five times the Australian average now and the magnitude of its effect on foetuses and infants establishing risk for their post natal life, and on children and adults damaging their current health regardless of what their early risk is, is probably huge.

Norman Swan: Wendy thank you.

Wendy Hoy: You're welcome.

Norman Swan: What a frustrating story. Dr Wendy Hoy is Professor of Medicine and Director of Chronic Disease at the University of Queensland.

Wendy Hoy spoke about the factors which determine the health and wellbeing or the lack of it in Aboriginal and Torres Strait Islander children and how that in turn determines the diseases they suffer as adults and die young from.

But the evidence backing up her claims has been patchy until recently. There's been a lot of fragmented research and a lot of opinion. But where are the facts? Just what things really make a difference to the physical and mental health of Aboriginal young people? Well that's what a unique study in Western Australia set out to find. They surveyed over 5000 Aboriginal children and young people and their families anywhere from remote communities to the city. Glen Pearson is the Project Manager for the West Australia Aboriginal Child Health Survey.

Glen Pearson: There's nothing of this comprehensiveness. It tells a story from an Aboriginal perspective.

Norman Swan: This in a sense was Aboriginal controlled research?

Glen Pearson: Absolutely, the steering committee headed by Associate Professor Ted Wilkes and senior Aboriginal community people led all aspects of the project.

Norman Swan: Which is a new way of doing research. I mean in the old days researchers would have said oh well, it's going to be biased and hopeless if you do that, it's got to be independent and we've got to tell you what to do.

Glen Pearson: Absolutely, you need to have Aboriginal people not only being involved in the process but in terms of the way that the questions were asked, in terms of the way they went about responding to the diversity of families across WA. So the people that were employed in the survey were also the people who had those skills in that area to make connection.

Norman Swan: Glen Pearson who also says that despite this diversity among Aboriginal communities the results are applicable to indigenous Australians across the nation.

One of the chief investigators in the Western Australian Aboriginal Child Health survey is Sven Silburn who's Director of the Curtin Centre for Developmental Health at the Telethon Institute for Child Health Research in Perth.

Sven Silburn: We got information on 5200 children under the age of 18 and we also collected extensive information from their families and with family permission we went to their schools and got reports on how they were doing at school.

Norman Swan: So this was a snapshot you were taking rather than following people for several years?

Sven Silburn: Exactly. However we got permission from these families to link to their hospital and birth records. That means that we have quite unique data around perinatal and pregnancy factors that are very important to subsequent health and mental health.

Norman Swan: So what are the key findings so far?

Sven Silburn: I think one of the things that really has come through very strongly is the importance of life stress and the living circumstances of child rearing. The extent to which stress is affecting health and development is quite extraordinary. We've got some very interesting data around the number of life stress events experienced by Aboriginal families with comparable information about non-Aboriginal families.

Norman Swan: So what sort of things?

Sven Silburn: We're talking about in the past twelve months has a family experienced a death, a hospitalisation, a family member being imprisoned, loss of employment, the real nasties of life stress events? And what we found is that something like 20% of Aboriginal children are in homes where they have experienced seven or more of those life stress events.

Norman Swan: And the equivalent children in white Australia?

Sven Silburn: .02%, so it's a thousandfold difference.

Norman Swan: And does that matter whether or not you're living in an urban situation or a remote community or what have you?

Sven Silburn: That tends to be much greater in the urban settings which is interesting because one of the myths has been that the worst health and mental health outcomes are in the most remote areas. That's not necessarily true, certainly as far as mental health we found that the best mental health for children and young people was actually in the most remote regions. The highest rates of problems was in the most urbanised areas.

Norman Swan: And the reason for that you think?

Sven Silburn: The compelling explanation is the intactness of culture, the continuity of family relationships and that many of these most remote setting were the least affected by policies of forced removal in the past.

Norman Swan: And what do these life stress factors correlate with?

Sven Silburn: A whole range of physical health outcomes, all of the complex diseases such as obesity, diabetes, heart disease, stroke, mental health problems and so on. All of them have a substantial proportion of their variance accounted for by these early childhood factors.

Norman Swan: And what about development?

Sven Silburn: These life stress events certainly impact on emotional development much more than they do on cognitive development but they also effect how children are able to concentrate and manage at school.

Norman Swan: What other key myths were you able to dispel?

Sven Silburn: There's been a long standing assumption by non indigenous people that all Aboriginal people live in vast, well supported extended families. In fact, particularly in the urban areas, we are seeing a rapid increase in single parent families who may or may not have access to the kinds of supports available in some of the extended family situations we see in the more remote areas.

Norman Swan: So a greater fragmentation of family life than you'd anticipated?

Sven Silburn: That's right. The other thing that I think is terribly important is the burden of disease carried by Aboriginal families. These families very often have chronically ill family members almost four times what you see in the non-Aboriginal population.

Norman Swan: So it's almost a quadruple whammy that you're talking about because of the physical burden that social and family support's available within the family are even less to cope.

Sven Silburn: Exactly.

Norman Swan: Sven one of the more controversial areas in this study has been forced separation.

Sven Silburn: What we did was to ask families whether a child's carer, that could be their parents, grandparents or either of their parents had been directly affected by forced removal or forced relocation from lands. And we also had information regarding whether a parent or the children had had contact with the mental health service.

Norman Swan: But isn't this group as a whole too young to have been involved in this generation?

Sven Silburn: Our analysis actually took that into account. In fact 85% of the carers of these children who said that they had been forcibly removed from family or relocated from lands were themselves born before 1969 and the vast majority of separations at that time would have been for reasons of assimilation rather than child protection. When we analysed those data separately we found exactly the same relationships and that is that children within those families

were two and a half times more likely to have experienced a mental health problem. Those parents were much more likely to have had contact with the mental health system, have been arrested, have alcohol and drinking problems and these data really show beyond doubt the enormous impact of those past policies on current rates of disadvantage.

Norman Swan: And any sense of it being transmitted?

Sven Silburn: Certainly the effects were greater in parents, the transmission was somewhat less in the following generation. I think that gives reasons for hope that over another few generations we might see those effects becoming less evident.

Norman Swan: Sven Silburn who's Director of the Curtin Centre for Developmental Health at the Telethon Institute for Child Health Research in Perth.

The most recent analysis of the survey findings has been for Aboriginal adolescents and young people. This was led by Eve Blair, Senior Research Fellow at the Telethon Institute.

Eve Blair: We found that Aboriginal young people did have a higher burden of physical ill health and also psychological disturbances. And then we looked back to see how many well adults there were looking after these disturbed young people and we found that there's very many fewer. Life expectancy is shorter, many of those Aboriginal adults who are supposed to be looking after these children are actually chronically ill themselves. So when we looked at the ratio of well adults to look after these disturbed young people we found that it's about only one quarter what it is in the non-Aboriginal community.

Norman Swan: So tell me about the findings you made on Aboriginal young people?

Eve Blair: They have a much higher rate of conduct disorders. That is you know lying, stealing, cheating, things like that. They also have much higher rates of depression especially among young women. We found that they have a higher rate of ear diseases, recurrent infections. People tend to think that that's true of young Aboriginal children but it's also true in the 12 to 17 age group. From the health risk factor point of view we find yes, there's more of them smoking, they are very much less likely to take regular physical exercise, but one of the other myth is, they are not more likely to drink, their drinking behaviour is actually very similar to that in the non-Aboriginal community of the same age.

However, we felt from the totality of the results from the survey was that the underlying causes, the causes that needed to be addressed to prevent these problems is not in the immediate obvious lifestyle factors but the social fabric underlying those. One surprising result of the survey was that young people's emotional behavioural problems actually decreased as they got older. Now that's fairly unusual and we felt that it was probably because they were going out into the community on their own, they were less involved with the family structure which had all these stressful life events happening.

Norman Swan: So how do you explain the alcohol?

Eve Blair: Rather than saying that there is no problem with alcohol is that the problem with alcohol is just as bad in non-Aboriginal communities as it is in the Aboriginal community. And I think one of the myths is that Aboriginal young people abuse alcohol and behave badly. I think that a lot of young people abuse alcohol and behave badly but if they happen to be Aboriginal then that will be underlined whereas if it's a non-Aboriginal person it's just young people behaving badly and that's what you expect.

Norman Swan: And what other findings that we haven't talked about do you think are important to highlight here in looking at young people?

Eve Blair: One of the findings is the totality of the disadvantages that young people face. Sven's already talked about the stresses, one of those stresses is racism whether it's real or perceived a lot of young people perceive that they are treated badly on account of their race which adds to their stress. I think the main message for government and non-government organisations is that the problems with health in Aboriginal young people is not just the problem of the health department it's a problem for all government departments including housing, infrastructure, education, family and children services and justice as well as health.

Norman Swan: Eve Blair is a senior research fellow at the Telethon Institute of Child Health Research in Perth.

So how do you act on all this information? Well getting action is one of the responsibilities of Colleen Hayward who managed the Kulunga Research Network also based at the Institute.

Colleen Hayward: Part of the work that we are doing is to actually assist government agencies but also community organisations in interpreting those findings in a way that can be useful to them.

Norman Swan: Government agencies all over the country have failed. Departments of Aboriginal Affairs have failed and most would say well thank you for giving us this survey data but we kind of knew it already – where do you go from here?

Colleen Hayward: You're right, that is actually the response that we are getting from some government agencies but it is borne of complacency on the one hand but also a recognition of the futility in which government bureaucrats have been operating. Because they do think that they've tried everything. What we're saying and what this data is saying is that in fact they haven't, or they've started from the wrong place.

Norman Swan: Some people are saying well the place to start is within Aboriginal communities themselves and there's almost nothing that the non-Aboriginal community can do apart from just get out of the way and let them swim.

Colleen Hayward: From an Aboriginal community perspective our mob would say what governments do very well is get in the way. Governments and communities have to end up increasingly working in partnership recognising that each side has responsibilities as well as rights.

Norman Swan: Now this is something that's inflaming some Aboriginal communities the so called SRA, the shared responsibility agreement so the Department of Aboriginal Affairs or whatever they're called comes in and says well we'll do this for you, we'll give you the petrol pump if you do this for us. And some Aboriginal communities are outraged by this and they say well we can understand the shared responsibility but it's tokenism, we are being treated like children and in fact it's taking away control from us. And there's enormous anger at these shared responsibilities.

Colleen Hayward: I think one of the bad things about shared responsibilities, the way they're operating is that because the Australian Government who was largely running this process is finding its way there are a lot of errors along the way. There's no standards, there is no set of basic or minimum inclusions in an SRA. There is for instance from a health perspective nothing that we've seen that indicates where the health content in an SRA might come from.

Norman Swan: Can you give me an example?

Colleen Hayward: Yeah, people think that gee it would be great if for instance in exchange for a petrol bowser or some other service it would be fantastic if Aboriginal parents made sure that their children were clean, had a bath, or a shower, or a wash everyday. Now that might on the surface sound fine to some people but it's not going to be workable where there is not easily available fresh water. No parent whether they're Aboriginal or non-Aboriginal makes a conscious decision to say it's OK for our kids to not shower or bathe every day but the reality is there are a number of people living in situations where that is not a real expectation.

One of the other dangers in this is certainly where there's been a lot of upset on the part of Aboriginal communities is that the trade is actually about basic human rights. No community whether they are Aboriginal or non-Aboriginal should have to bargain a particular way of behaving or acting in exchange for receiving.

Norman Swan: Stuff that the direct general community gets.

Colleen Hayward; Basic amenities. Power, water, sewage, rubbish removal, proper accommodation, those things aren't on the table for any other group, they certainly should not be for us.

Norman Swan: Just picking up from Sven's comment that whilst there are excessive problems compared to the non-Aboriginal community wherever you look, they're greater in urban communities where there's more fragmentation,. It's much easier to have these shared responsibility agreements in remote more coherent communities than it is in a suburb of Perth. How do you deal with it in Aboriginal communities in an urban situation?

Colleen Hayward: You're quite right, it's much easier where members of a community are easily defined in terms of geographic isolation for instance. However while the Australian and other jurisdictional governments insist on recognising Aboriginal people in remote locations to the exclusion of recognising other Aboriginal people it's a fundamentally racist policy. And governments have to get past that in their own thinking before things will really have an opportunity to improve.

Norman Swan: I'm not quite sure what you're saying, in other words you're saying that they ignore Aboriginal people in metropolitan areas?

Colleen Hayward: Largely, I think there is a wrong assumption that because you live in an area where services maybe accessible, that those services are actually going to be able to be accessed by Aboriginal people, there's a whole range of reasons why they're not. So more effort does need to be made across all areas. Governments need to broaden their thinking, this is not about only those people closer to living in a traditional cultural sense are the real Aboriginal people and others are less.

Norman Swan: But in the end whether you're talking about indigenous communities or non-indigenous communities whilst you've got the super imposition of human rights, racism and so on which you cannot minimise, there are some fundamental things to do with parenting style, with social cohesion, with family support, with high expectations of children that you are going to do well at school and so and so forth, it seemed to predict good outcomes. And if you're going to go from a general principle that Aboriginal communities kind of need to determine their own future and take control of things, how do you start remediating that?

Colleen Hayward: Everyone whether they're in government or not need to recognise that special measures are still necessary for many people in the Aboriginal community because it is not a level playing field. Equal treatment of people that doesn't recognise that people come from a basic position of inequality only perpetuates that inequality. There is still a need for special measures and quite frankly there is still much need for community and capacity building across a range of Aboriginal communities.

Norman Swan: Helping people to help themselves?

Colleen Hayward: Absolutely and that needs to be done long term, possibly generations.

Norman Swan: Colleen Hayward manages the Kulunga Research Network based at the Telethon Institute for Child Health Research in Perth.

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Further information:
Western Australian Aboriginal Child Health Survey
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