SUBMISSION TO

THE SENATE SELECT COMMITTEE ON
REGIONAL AND REMOTE INDIGENOUS COMMUNITIES

Submitted by
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UNITING ABORIGINAL & ISLANDER

CHRISTIAN CONGRESS (S.A.)

I write to the Senate Select Committee on Regional and Remote Indigenous Communities in response to term of reference 1b:

> *to inquire into and report on - the impact of state and territory government policies on the wellbeing of regional and remote Indigenous communities;*

My submission does not relate to the Northern Territory Emergency Response but seeks to highlight my concerns about how State and Territory Government policies are undermining the wellbeing of Aboriginal individuals and families from remote Indigenous communities who are forced to relocate to major population centres for dialysis due to end stage renal disease and inappropriate government policies.

In my work as a minister with the Uniting Aboriginal and Islander Christian Congress in a congregation which meets at Salisbury North I have a lot of involvement with Anangu families that live in Adelaide. These families have generally moved to Adelaide within the last five years from communities in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands.

Many of these families live in Adelaide because of serious health issues. Currently there are seven people from the APY lands and cross-border region involved with our congregation who are on dialysis. (One man originally comes from further north, but has an Anangu partner and has been part of a particular APY community for years. Another old man from the APY Lands who is on dialysis attended our church last year but is now living with his wife in Port Augusta.)

Historically most Anangu have gone to Alice Springs for dialysis. The Northern Territory Government stopped accepting dialysis patients from South Australia and Western Australia in about February 2009.

I am concerned that Anangu going on to dialysis now have little choice about their future: either they must exist in exile far, far from their home communities and their country, or they can go home and die. They have no other choice.[i]

Out of my pastoral involvement with people in my congregation, I have found myself involved in this issue and trying to support some of these people and their families as

they call for renal dialysis services to be provided in the APY Lands and for the return of access to renal dialysis services in Alice Springs.

I also have visited a number of Anangu and cross-border people in hospital or hostels here in Adelaide who are going to be commencing dialysis soon and will end up living in Adelaide. I can think of five people in this situation that I have visited in the last four months. In a meeting recently between SA Health and Uniting Care Wesley Adelaide, Dr Sherbon (CEO, SA Health) was reported to have indicated that SA Health was preparing to respond to "up to 20 more dialysis patients from the APY Lands by the end of 2011".[ii]

I see first hand the effects of this dislocation. A number of these people have spent all or much of their lives in traditionally oriented bush communities. Going on to dialysis is a huge and confronting thing for them. Having to leave home and family and come to Adelaide is another huge and confronting thing for them.

As Anangu make the transition into being on dialysis they are often very worried and fearful and want family to be with them. They usually arrive with no arrangements in place except that they live individually or with an escort in an Aboriginal Hostel. These hostel arrangements often don't last long once the wider family arrive. The dialysis patient then has to start from the beginning, getting their Housing SA applications in and trying to get a priority one listing for a house for themselves and their family. In the meantime, in Adelaide, they often float from existing Anangu household to another Anangu household, pushing up levels of overcrowding, and possibly rubbish issues and neighbour complaints - and thus sometimes contributing to the likelihood of an existing tenancy being lost. Neither Aboriginal Hostels, nor Kanggawodli nor the proposed new Transitional Accommodation Centre(s) in Adelaide are designed for or appropriate for, the needs of this particular clientele group (as evidenced by the short durations that most dialysis patients stay in such places).

I am aware of at least three Anangu households in Adelaide who have dialysis patients residing in them who have been provided with formal warnings in the last three months for not complying with their tenancy conditions. Considering there are only five households with people on dialysis in them, this represents 60% of such households facing the risk of eviction[iii]. I believe this pattern will continue as the numbers of Anangu dialysis patients and families in Adelaide escalate unless carefully considered and appropriate, Anangu-friendly properly funded support mechanisms are put in place around these families[iv].

Many of the Anangu dialysis patients had a well defined identity and respected place in their home community in the APY Lands. Down in Adelaide they find themselves profoundly dislocated and often feeling really lost and disrespected – as though they are just "a problem" or a "nobody". Indeed, they are strangers in other peoples' country. The language and rules are different. They feel powerless and unable to play a positive and significant role in life in this strange land. I have observed that for some of the Anangu in Adelaide on dialysis, the worry and pressure results in a state of profound hopelessness, despair and anger and for some, bouts of drunkenness and depression that are out of character with their usual life stance.

Being on dialysis, Anangu also have to face and come to terms with the reality that this is a long-term exile. Adelaide is so far from the APY Lands communities that there is not enough time between dialysis sessions to make a quick trip up and back without missing

dialysis. So to go back for respite, or sorry business, or important community meetings or events, Anangu dialysis patients have to choose either not to attend or to put themselves under the pressure of not complying with their normal dialysis regime. I think of one woman in our congregation who lost her daughter and husband last year and the sadness she felt in not being able to fulfil her obligations for sorry business in the way she would have if she were not on dialysis.

And this new reality isn't just "for a season" – it is for the rest of their lives - unless they receive a kidney transplant – which doesn't happen often.

I have assisted some of the members in my congregation to write letters to relevant ministers about some of these issues. These letters are appended.[v] Please read them.

From my conversations and observations with Anangu dialysis patients it seems clear that they would like to have the option of receiving dialysis in the APY Lands as well as, if and when appropriate, coming to Adelaide or to Alice Springs for dialysis.

This is reflected in the letters from members of my congregation I have previously referred to. It is also very strongly the message conveyed in a letter I have seen, addressed to Minister Snowdon, signed by Anangu residents in Topsy Smith Hostel at Alice Springs[vi]. The letter says

> We are eleven women and two men living at Topsy Smith Hostel the main residence for renal patients and their carers in Alice Springs.
>
> We, who come from the tri-state (WA, APY Lands in SA, and NT) borders area, are sad and worried. We know that many more people from our home communities will need dialysis soon.
>
> They ALL should be able to come here for treatment but governments say no, only people who live in the Northern Territory can come to Alice Springs now.
>
> It hurts our spirit (*kurunpa uparingkula tjituru-tjituru)* and we think it is cruel to send Anangu from SA-APY Lands to Adelaide or Port Augusta.
>
> People get very sad and weak so far from their country and family, and their families can't visit them down there – it's too far.
>
> If people have to go to Adelaide their whole family goes with them. That leaves a big hole in their community. We know of one lady at Ernabella who will go to Adelaide soon for dialysis; one of her daughters who has been a senior teacher in the community school for many, many years and is one of the strong community leaders is going to leave her school job after Easter to look after her mother in Adelaide.

The letter describes the effects of dialysis patients being absent from their home communities and then makes the following plea:

The best would be to have dialysis units in every main remote community.

That would save a lot of heartache and a lot of money: our money, and the governments' money

Please start listening to us about dialysis treatment in our communities.

Anangu must be trained and supported to do this work. Why not?

Will you please answer this serious question?

All of us can help you with this work.

You can't do it by yourselves; neither can we.

Perhaps not all politicians and government people understand how our families are scattered and our communities made weak because of the way our struggle with kidney diseases and diabetes is handled by governments and health services.
That's why we are writing this letter; we want you to understand.

We do believe that if you listen with an open heart and open ears you will understand properly. Then we can work together to get this right[vii].

I would have thought the Anangu dialysis patients in my congregation and those living at the Topsy Smith Hostel residents would have been listened to with great care by the relevant policy makers and service deliverers. After all, they are from the APY Lands and the cross border region and are the ones most affected by government policies concerning dialysis. Sadly, the evidence suggests otherwise.

Minister Roxon's office says [viii]

> Dialysis services are predominantly administered by state and territory governments... and under the current arrangements, State and Territory Governments have the authority to determine policy regarding the provision of he services that they operate.

And that

> Minister Snowdon is encouraging and supporting States and Territories to reach swift agreement on a sustainable, long-term resolution to this situation for dialysis patients in Central Australia.

Some three months later, in a recent report aired on ABC TV's Northern Territory edition of *Stateline*,[ix] Minister Snowdon said:

> I don't think it's open to us to direct the ministers in the State and Territory jurisdictions, it's certainly open for us to have a discussion with them, and we will.

My question is - **when?**

I also need to say that I am not that interested in discussions – if they just become a substitute or excuse for doing nothing. What the situation requires is real outcomes that benefit the people who have end stage renal disease, and their families.

Meanwhile the South Australian Government's Minister for Health, Minister John Hill MP seems to be deaf to the concerns and aspirations of the Anangu dialysis patients. Rather than seek an urgent resolution to the issue of access to Alice Springs, the South Australian Government has quite deceptively trumpeted that it is providing "more renal dialysis for patients from the APY lands"[x] when it has really opted for an attrition by death policy of decreasing the number of Anangu on dialysis in Alice Springs from the current 18 to 8.[xixii] Furthermore, Dr Sherbon confirmed in the meeting between Uniting Care Wesley Adelaide and SA Health that SA Health had not asked for any more than 8 places[xiii].

In the same media release Mr Hill evades the real issues and spins on about renal services for Port Pirie, Whyalla and Port Augusta. These places are between 800 and 1500 kilometres from the APY Lands communities that affected Anangu come from!

And somewhere off in the future Mr Hill suggests that SA Health "will look into the possibility of providing renal dialysis closer to the Lands, at Coober Pedy and – in the longer term – on the Lands too."[xiv]

Apparently the Coober Pedy option is at least three years away... and the APY Lands options even further away in some far distant future.

I am struck by the bureaucratic, apathetic, business-as-usual language of the various Ministers and bureaucrats, that seems to take no account of the real life flesh and blood people, and their feelings and losses, as their lives are totally turned upside down and inside out permanently by the reality of 'going on dialysis'.

Mr Hill says SA Health will be completely guided by what Nganampa Health Council believes is the best approach. In Pitjantjatjara "Nganampa" means "our". Curiously, it seems dialysis patients are not part of the "our". I find it hard to understand how so many Anangu with end stage renal disease can be asking for dialysis on the APY Lands, and for access to Alice Springs, and describing the difficulties of the current situation, and yet it appears that Nganampa Health Council is refusing to support them[xv] In the record of the meeting between Uniting Care Wesley and SA Health: "Dr Sherbon noted that Nganampa Health Council's Medical Director (Dr Paul Torzillo) does not support the establishment of dialysis services on the Lands". This leaves me wondering who the "our" is in Nganampa Health Council.

I believe it is really important to realise that the costs associated with Anangu being on dialysis are significantly more than just those relating to the provision of medical services whether we are talking about dialysis in Alice Springs, Adelaide or Port Augusta.

I believe there needs to be a proper assessment of the associated issues and costs that accompany a dialysis patient from the APY Lands. I believe patients should have a package of support provided so that appropriate wrap around services can be provided to them wherever their dialysis service is provided[xvi].

The hidden cost burdens need to be properly examined. A true comparison of costs and benefits cannot be made unless all costs and benefits are factored in for each available option - dialysis on the APY Lands, dialysis at Alice Springs and dialysis in Adelaide/Port Augusta. It can look more economically attractive to have Anangu dialyse in Adelaide – if the only costs recognised are medical expenses associated with dialysis – and if the other costs remain hidden. Some of these costs include other support and services provided to the patient and family by SA Health, Housing SA, Families SA, SA Police, various charities and community service organisations, Aboriginal organisations and the like. When the reality of these costs are taken into account the story may be quite different.

Picking up on this issue, a resolution was adopted at the February 2010 meeting of the SA Synod of the Uniting Church. The resolution called on the State and Federal Governments to:

- *Remove the barriers that currently prevent critically-ill people from South Australia's APY Lands from accessing renal dialysis in Alice Springs.*
- *Investigate the pros and cons – and comparative costs – of providing renal dialysis in a range of settings, including in remote Aboriginal communities like the APY lands*[xvii].

I believe the Federal Government needs to step in and take a much more pro-active role in this issue. The increased and increasing demand for renal dialysis services has created a crisis – the South Australian Government is avoiding facing the issue adequately, and Territory Government seems overwhelmed. I believe the true measure of a community is how it treats those who are on the margins, the least, the sick and those with little power. I'm honoured to be a friend and a pastor for a number of these folk. I believe they deserve better. For the sake of the dialysis patients, their families and communities the Federal government needs to act.

I see three rays of hope in this gloomy situation.

The first is the fantastic work done by the Western Desert Nganampa Walytja Palyantjaku Tjutaku who have been proactive and pioneering in this area for some years now. They have researched, identified and articulated key issues and appropriate service responses for Aboriginal people on dialysis for a long time. Importantly they have taken time to really listen and understand what the dialysis patients were saying and feeling, and respected the Yanangu world view. Their reports indicate that exiled dialysis patients in urban settings need advocacy and support as they arrive and commence dialysis, attempt to find housing and some equilibrium and face the tough new situations that they encounter. Their research tapped into the deep feelings of patients and their families, and looked closely at the patient journey and the medical system's responses. Their research highlights and seek to address the desire for dialysis in home communities. They emphasise the importance of culture and provide opportunities for patients to go "back to country" and sustain family connections, and deal with grief. I believe this quality research provides some benchmarks for world's best practice in understanding traditional/remote Aboriginal dialysis patients and in the delivery of renal services to such folk. [xviii] I believe policy makers and service deliverers would do well to give significant attention to the reports and activities of Western Desert Nganampa Walytja Palyantjaku Tjutaku.

The second hopeful sign for me was a comment by SA Health and concerns dialysis in Alice Springs and is in the record of the meeting between Uniting Care Wesley Adelaide and SA Health[xix].

> Mr Nicholls asked if there were any conditions under which SA Health would consider funding the construction of a dialysis facility in Alice Springs exclusively – or predominantly – for people from the APY Lands. Dr Sherbon indicated that this would not happen. ***Mr Nicholls asked Dr Sherbon to confirm that if the Federal Government funded the capital costs of such a facility, SA Health would be prepared to cover the recurrent funding. Dr Sherbon confirmed that this was the case.*** (emphasis mine)

Given this response from Dr Sherbon, I believe the Federal Government has to intervene decisively and provide more significant capital funding for increased renal dialysis facilities, (bricks and mortar, and mobile) in Alice Springs to serve Anangu and cross-border people.

The third source of hope for me is the excellent description of the issues contained in the first six monthly report of the Coordinator-General for Remote Indigenous Services.

> ***End Stage Renal Disease Services***
>
> Renal disease is a major concern in almost every community I visited. The incidence of treated end stage renal disease in Indigenous Australians is more than eight times that of other Australians. In the Northern Territory it is more than 28 times.
>
> Given the prevalence of renal disease in Aboriginal communities and the social and economic costs of patients relocating to regional centres for treatment, patients and communities are seeking local provision of services where possible. There is also concern in the Central Desert region at current arrangements that see renal services in Alice Springs effectively closed for patients from cross border regions. While negotiations continue between the Northern Territory and Western and South Australian Governments, patients are being sent further away from family and cultural affiliations to Perth and Adelaide.
>
> State and Territory Governments are responsible for providing tertiary services within their jurisdictions and determining policy regarding the provision of these services. This includes delivering renal dialysis and associated support services within hospital and community settings. The Commonwealth Government provides funding to State and Territory Governments through the Intergovernmental Agreement on Federal Financial Relations for tertiary services delivered in a manner consistent with the terms of the National Healthcare Agreement, which includes the provision of renal dialysis services. The Commonwealth Department of Health and Ageing is also providing approximately $10 million through to 2011-12 in additional funding for renal services for Indigenous patients in rural and remote areas in the Northern Territory.
>
> The policies of both levels of government state that if patients are able to learn self care dialysis, they will be supported to return to and access services in their communities on the condition that sufficient family and clinical support is available to

enable dialysis to occur safely. However, only a proportion of clients are deemed suitable for self care dialysis and are able to return home.

Both levels of government argue that providing care for Indigenous people in their communities can be unsafe, expensive and impractical given constraints such as the need for a specialist workforce, infrastructure and support, however, there are examples of services that are operating successfully.

In reality some patients will choose not to receive care if they cannot access it locally, which means they are likely to die prematurely and painfully. Patient wishes and quality of life should be considered when determining the most appropriate approach to care. It should also be borne in mind that the costs associated with treatment provided in regional centres can be considerable and often involve the movement of families.

Governments should make every effort to implement measures which might extend the lives of Aboriginal people when the current policy framework agreed by COAG has, as its goal, the closing of the life expectancy gap between Indigenous and non-Indigenous Australians.

I do not want to constrain discussion between governments on the exact nature of measures that may be required to resolve the complex problem of treatment of renal disease in remote Aboriginal communities but I urge action on two key fronts:

- immediate consideration of strategies to boost renal services in Alice Springs including for patients travelling from the desert regions in nearby Western Australia and South Australia; and

- further consideration by State and Territory Governments in partnership with the Commonwealth of the costs (including patient and family movements) and benefits of providing care in priority communities and the merits of co-locating renal services with primary health clinics in these locations.[xx]

I believe it is essential that the federal Government ensure the State and Territory Government are taking seriously the need for dialysis services as close to home as possible for dialysis patients, commit to addressing this issue appropriately, and explore fully the range of options that most comprehensively and adequately deal with the issues involved, and expedite and fund effective policy responses and service delivery.

Thank you for this opportunity to contribute this submission. I would be happy to speak with the committee if you considered it would be of value.

I wish you all the best in your deliberations.

Rev. Dean Whittaker
1/4/2010

[i] Although I have no medical expertise, I believe the world view and living conditions of most Anangu living in the APY Lands or cross-border region make infection a high risk and militate against self-managed, sustainable and safe peritoneal dialysis. This is why I say they have no other choice. I see the choice being between haemodialysis or death. (Henceforth in this submission when I write dialysis I am meaning haemodialysis).

[ii] See Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010, p3. http://www.papertracker.com.au/pdfs/SAHealth1.pdf

[iii] See appendix 1 Housing SA "letter of warning"

[iv] While it seems in vogue to describe remote Aboriginal communities and families generally as dysfunctional, I find it interesting that such communities and families with some (usually minimal) external support and resourcing often have the capacity to provide what Anangu dialysis patients want, (a sense of being home, in the midst of valued family connections, belonging in a place they feel safe, and continuing involvement and roles in the life of their own community), in a way that prevents the development of the much bigger problems which emerge and then seem so impossible to address when such patients and their families end up in an urban centre – even with intensive support from large, well resourced and State-backed entities. It seems to me that Housing SA staff in Adelaide are really struggling with how to deal constructively with the Anangu families whose tenancies are at risk and would greatly value more support and options.

[v] See appendix 2 Brown, C. 8 November 2009. Letter to Hon Jenny Macklin MP
See appendix 3 Burton, L. 2 February 2010. Letter to Hon John Hill MP.
See appendix 4 Brown, Y. 27 January 2010. Letter to Hon John Hill MP

[vi] Australia Day Letter from residents of Topsy Smith Aboriginal Hostel to Minister Snowdon 26/1/2010 signed by Pantjiti McKenzie, Nyukana Baker, Jillian Seven, Kutungu Munti, Maringka Bennett, Marlene Pareroultja, Sarah Goodwin, Goodwin, Shirley Watson, Rosie Patterson, Rene Kulitja, Kanytjupai Armstrong, Simon McKenzie and Richard Kulitja

[vii] Ibid

[viii] Letter in response to Colin Brown's letter - on behalf of Hon Nicola Roxon, MP, from Joan Corbett, Assistant Secretary, Program and Planning Branch, Office for Aboriginal and Torres Strait Islander Health, 17 December 2009.

[ix] Stateline NT Friday, March 19, 2010 10:25 AEDT at http://www.abc.net.au/news/video/2010/03/19/2851258.htm?site=newengland

[x] See Appendix 5 ALP SA News Release Mr Hill Friday, 12 March 2010 entitled MORE RENAL DIALYSIS FOR PATIENTS FROM THE APY LANDS

[xi] See Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010 http://www.papertracker.com.au/pdfs/SAHealth1.pdf p3

[xii] The number of Anangu dialysis patients in Alice Springs is 18 according to the document "*Matters of fact as raised during meeting with SA Health*" at http://www.papertracker.com.au/pdfs/SAHealth2.pdf p3 which corrected the earlier figure of 14-16 nominated in the conversation at the time of the meeting between SA Health and UnitingCare Wesley Adelaide.

[xiii] Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010 http://www.papertracker.com.au/pdfs/SAHealth1.pdf p4

[xiv] ALP SA News Release Mr Hill Friday, 12 March 2010 entitled MORE RENAL DIALYSIS FOR PATIENTS FROM THE APY LANDS

[xv] On 27/2/2010, I emailed John Wilson of Nganampa Health seeking information on Nganampa's policy position on renal dialysis services in the lands. To date I have received no response from Mr Wilson or Nganampa Health. An excerpt from my email read as follows:

> I note that in the draft strategic plan of April/May 2006 - Wiru Palyantjaku resolved that they wanted dialysis to be provided ON the APY Lands by 2011. See the last two pages of the attached document wpwkshpaprilmay2006.pdf (Wiru Palyantjaku's *draft* Strategic Plan). At the time, or soon thereafter, I expect that Nganampa must have had a policy position in relation to such a proposal.
>
> Could you please clarify for me whether Nganampa Health Council has had a policy regarding the provision of renal services on the APY Lands in the past. Does it have a current policy? Could you please provide me with a copy of any past or current policy decisions by Nganampa Health Council in relation to the provision of renal dialysis services on the APY Lands.
>
> Also could you please provide me with Nganampa Health Council's current policy regarding access for Anangu to renal services in Alice Springs.
>
> Thanks, Dean

[xvi] See appendix 6 Whittaker, D *Support for Anangu living in Adelaide*

[xvii] See Appendix 7 Uniting Church Media Release "*GOVT FAILING TO PROVIDE ADEQUATE HEALTH CARE FOR INDIGENOUS PEOPLE IN REMOTE SA*"

[xviii] Paul Rivalland (2006) *It's more than machines and medicine: They should understand there's a Yanangu Way – Summary Report November 2006* Western Desert Nganampa Walytja Palyantjaku Tjutaku
at http://www.crcah.org.au/publications/downloads/WDNWPT_Short_Report_low-res.pdf

[xix] Record of meeting between SA Health and UnitingCare Wesley Adelaide held on 15 March 2010 http://www.papertracker.com.au/pdfs/SAHealth1.pdf p5

[xx] Coordinator General for Remote Indigenous Communities , Brian Gleeson's first six monthly report at http://www.cgris.gov.au/site/progress.asp p77