

Aoc 5/3/09

SUMMARY OF SUGGESTIONS FOR INDIGENOUS CARERS

As an Indigenous Carer I have made a personal commitment to provide support and care for another and obviously this will remain my primary concern, however if the government requires that I be gainfully occupied with job search, study or training, then they need to remove the barriers, provide more practical measures and create strategies that will encourage and improve the social and economic participation of all Indigenous Carers.

I suggest that this may be achieved in the following ways:

- Increasing the number of Indigenous Health Workers (IHW) within the aged and disability sector would serve to increase Indigenous usage of supportive services;
- Financial assistance or government subsidisation for respite care purposes would make in-home respite care a more attractive option, relieving the worries and concerns of the Indigenous Carer so that they are able to focus on other aspects of their lives;
- Making it easier for Indigenous Carers to access in-home respite care provided by IHWs by easing Indigenous agencies HACC eligibility requirements such as boundary restrictions;
- If Indigenous Carers are asked to utilise mainstream organisations, then cross-cultural training ought to be made available or made compulsory for all non-Indigenous staff just as it is for teachers, nurses and the police services, for they are going to be dealing with our most vulnerable and valued community members;
- Making it easier for an IHW to be brokered through a mainstream service provider in order to service their Indigenous clients;
- The creation of more Indigenous agencies that are equipped and staffed to provide the kind of services and support needed for Indigenous Carers of the frail aged and disabled; otherwise
- Increasing funding to established identified agencies to provide these services;
- Assigning a Case Manager to an Indigenous Carer in a similar fashion to those assigned to the long-term unemployed which would greatly assist an Indigenous Carer in transitioning back to the work force because personal support may be required to address issues such as Grief and Loss, how to job search and retraining. Preferably the Case Manager position would be an identified position and filled by Indigenous staff;
- The Australian government is currently trialing the Access Points Project – a one stop shop for service delivery to the frail aged and disabled. It could be adapted to create the type of Indigenous agency mentioned in the previous points and be used as a referral point for daily and living aids, offer in-home respite care, transportation assistance with the ability to transport patients in wheelchairs, and also offer personal support via assignment of an Indigenous Case Manager for both the Carer and those being cared for;
- A publicity campaign highlighting the available services for the frail aged and disabled and how they can be accessed because people need to know what help is available.

I am hoping that the Standing Committee will take into account the issues and concerns that I raised and seriously consider the suggestions that I have put forward and use this opportunity to give better support to Indigenous Carers which will in turn improve the quality of life for the Indigenous frail aged and disabled.

Committee Secretary
Inquiry into Better Support for Carers
Standing Committee on Family Housing and Youth
House of Representatives,
PO Box 6021, Parliament House,
Canberra ACT 2600.

February 21, 2009

Dear Secretary,

In addressing the terms of reference for this Inquiry I have endeavoured to bring your attention to my experiences as an Indigenous Carer so that you might better understand the challenges I face in accessing and securing the community assistance required in order to satisfactorily care for my mother. The role of Indigenous Carer is extremely stressful and the immeasurable contribution we make to the Indigenous community and Australian society at large by caring for the Indigenous frail aged and disabled at home has gone unrecognised and unaided for far too long. Therefore, I make this submission with optimism that the Standing Committee for the Inquiry of Better Support for Carers will consider the issues and concerns that I raise and that they will resolve to find ways that might better support myself and other Indigenous Carers so that we may continue to care for our loved ones in their own homes.

I am a 45 year old Indigenous woman, living in Brisbane and caring for my 66 year old mother, who just like so many other Indigenous people, suffers from diabetes of which complications have left her near-blind. Furthermore, after suffering several strokes her mobility has been compromised and restricts her to the house where we have lived for over thirty years though her recent diagnosis of dementia means that she no longer recognises this house as being our home. Subsequently she does not remember the times (good and bad) spent raising her eight children and numerous grandchildren, along with the sharing and caring she provided for her extended family and others within these four walls and under this roof. Nowadays we live by ourselves and the high level care that she requires is provided by me alone, albeit with advice from our local GP.

Eight years ago my family cared for and nursed my eldest brother at home after he became quadriplegic due to a suicide attempt. Two years after he passed away I helped to nurse my father whilst he was dying from advanced brain and lung cancer. On both occasions culturally-appropriate support was very limited and most times we made do or went without. As a result, my siblings and I now possess first-hand knowledge and experience of secondary trauma and emotional burnout which has left my family hopelessly fragmented and more prone than ever to alcohol, drugs and violence whilst attempting to deal with subsequent feelings of 'paralysis' and pain. I recognise that my brothers and sisters coping skills have been compromised and their reluctance to share the emotional burden and ongoing trauma of providing care for another beloved family member whose health will only deteriorate with time is just simply emotional survival. It does not mean that they love our mother any less than I do. In spite of that there are times when I need to make every effort to not share their belief that there is nothing we can do to affect the shape of our lives or events and situations around us.

My mother's story and her need for assistance is typical in that positive health outcomes are often beyond the reach of our Indigenous Elders who, after years of service to others and their

communities, they (or their Carers) are either reluctant to or have an inability to access vital health services and many of just give up, go without and suffer in silence. However, if successful in navigating the labyrinth of bureaucracy and accessing those agencies identified as being the most appropriate, having to confront institutional racism in an attempt to have our needs understood and addressed is extremely traumatic for both the Carer and those being cared for.

When I first started to care for Mum I was a full-time university student, however Mum's deteriorating eyesight meant that I was unable to leave her alone to attend classes on campus, so I was forced to withdraw from my course of study. Reluctant to cease studies altogether I was fortunate enough to find an institution that offered my preferred course of study externally but realised that in order to have the necessary time to devote to my studies I needed support to care for Mum. My main requirement was transport assistance to facilitate her attendance at medical appointments (GP, pathology and specialist) as well as the provision of in-home respite care whilst I pay bills, complete the weekly shopping and/or run other errands. So I approached Burringilly, an Indigenous organisation that provides Home and Community Care (HACC) services to Indigenous people. However I was informed that my mother was not eligible to receive any assistance because Burringilly is located in south-west Brisbane and we reside at Cannon Hill which is located in south-east Brisbane and lies well outside of their client catchment area.

At that stage Mum's health wasn't too bad and an Aged Care Assessment Team (ACAT) evaluation deemed her ineligible for assistance because she still had a degree of physical ability and mental autonomy. However I believe the stress of her rapidly deteriorating eyesight and the awareness of her resulting dependency played havoc with her diabetes causing her to suffer a series of small strokes after which I noticed alarming changes in her mental acuity and behaviour. Her GP then made arrangements for a number of different tests and specialist consultations and we utilised the patient shuttle service belonging to the Aboriginal and Islander Community Health Service (AICHS) whenever Mum was required to attend these appointments. Yet after doing this on numerous occasions, I was suddenly informed that we were not deemed to be patients of AICHS because we had not presented for medical attention in some time and the transport service was reserved for the use of current patients only. This left both Mum and I shocked and angry and I have attached a copy of the complaint that was presented to AICHS Executive Council in response (*see attachment A*) in order for you to gain an appreciation of the personal repercussions this withdrawal of assistance had. The Standing Committee for this Inquiry should also recognise that the pressures Indigenous Carers are placed under whilst seeking medical assistance and/or community support for those in their charge is in addition to the unrelenting strain of ongoing socioeconomic disadvantage and so it becomes a struggle to live each day in an environment of demoralising helplessness.

I understand fully that there are others who survive in situations even more distressing than my family's yet to be ignored is something I expect from white Australia and its agencies, so I am angered and disillusioned by Indigenous organisations in Brisbane who fail to recognise and acknowledge the fact that so many Indigenous Carers are doing it tough. For it seems as if the Indigenous frail aged and disabled and their Carers are continually overlooked in favour of the more able-bodied. While it can be stated that our most vulnerable members are the Indigenous disabled, so it must also be acknowledged that the more deserving of the Indigenous community are our Elders for they are the pillars that continue to support our communities and the ones who can remind us of what it is to be an Aboriginal or Torres Strait Islander person. Hence it remains a source of disgust that funding and the creation of infrastructure with the resulting service

provision is seldom aimed at caring for and supporting those of us who tend to the needs of a 'minority within a minority'. For the primary consideration for an Indigenous Carer when seeking assistance is whether or not it can be provided in a culturally-appropriate manner acceptable to those needing care and it is not being able to obtain this assistance or support for my mother that stresses me most.

After informing my mother's GP of the difficulty that I was having he then arranged another ACAT evaluation and she was duly rated as needing high level care and considered eligible to access a Community Aged Care Package (CACP). The local provider we chose had no Indigenous workers but we accepted this and allowed them into our home twice a week because I felt that I needed the assistance and was not fussed about the source. However we soon found having people with second-hand 'knowledge' and ill-informed opinions about Indigenous people in our homes intolerable. Even though their expected duties included a modicum of cleaning along with bathing and dressing Mum, she still preferred that I do those things. Subsequently when the workers would arrive all I wanted them to do was to sit and chat with Mum, make her the occasional cup of coffee and, because she has forgotten where she is, take her to the toilet if she needed while I either do the errands or catch up with my university studies. However it must be said that during these home visits we endured the occasional socially awkward remark along with the most illogical questions about Indigenous people, and even had one worker take a nap on our couch instead of doing what was required, which was to tend to my mother. In spite of this the deciding factors to end this 'community assistance' was the insensitivity and lack of understanding shown by workers on two subsequent occasions.

The first instance occurred just before Christmas last year upon resumption of home visits after I had suspended them for several weeks due to a death in the family the month before. When asked by a worker if we had been away I informed her that I had requested services to be stopped because my family was in mourning but did not want to talk about it. As it was, a family member was the victim of a murder in a highly publicised case and I did not wish to give her any details so that she could indulge in salacious gossip with other strangers. Yet as soon as I left to do the shopping she proceeded to interrogate my mother about the death which upset her and made her cry, however Mum did not tell me about this incident until after the worker left.

The following day I was informed that I was successful in securing one month's respite care for Mum in a nursing facility in Salisbury which was approximately an hour's drive away so I did not contact the service provider to complain about the worker's actions because we needed their transport assistance. It was my intention to have two week's respite before Christmas to enable me to do the Christmas shopping and get the house ready for my sister, her husband and their children who were spending Christmas with us. Mum would then come home for a week on Christmas Eve, then returning to the nursing facility for another week sometime during the first week in January to give me a chance to clean up after our visitors had gone home.

But during Christmas my brother in-law got the news that his father was terminally ill on Palm Island yet it was unsure how much time he had left. Because my sister and her family live in Rockhampton, they could not afford to leave Brisbane to go to Palm Island to see her father in-law and then return again for the funeral. As a result my brother in-law decided to wait until his father had died but was fully expecting this to not happen until the end of January sometime and certainly not until after they had returned to Rockhampton. In view of this decision, everyone agreed when their six year old daughter asked if she could stay with Mum and I a bit longer. As I was also expecting an older niece to arrive from Alice Springs to spend some time with us during

the post-Christmas period, I assumed that she would be able to take care of Mum for a few days while I took the little girl back to Rockhampton a fortnight later. However when my sister and her family were driving home to Rockhampton they received the phone call to let them know the old man had passed away, so of course the little girl had to be taken back to Rockhampton as soon as possible.

When I was able to contact my older niece a few days later, she told me that because of her employment obligations she could not come to Brisbane until March of this year. So I then moved to secure another week's respite care for Mum in order to take the little girl home to Rockhampton as soon as I could because funeral arrangements had already been delayed to allow time for all family members to attend. So the following Friday we caught the train from Brisbane to Rockhampton where I spent the night and caught the Saturday early morning train back to Brisbane. Then in the early hours of Sunday morning I received another phone call from my brother in-law letting me know that while they were travelling to Townsville their eldest daughter had gone into labour prematurely and had given birth to her baby in Ayr hospital. Because they were racing against time they were forced to leave them both and continue on to Palm Island for the funeral but would not be able to leave the island for at least another ten days. So they asked if I could get my hands on essentials for the baby, go to Ayr, pick up my niece and her baby and bring them both back to Brisbane because she was in a terrible state due to losing her grandfather and not being able to attend his funeral and they were worried about her. So of course I agreed as I knew that there was no-one else they could ask this of.

After I had secured a further week's extension of respite care for Mum, I had to ensure that any travel arrangements for the following Thursday coincided with my niece's release from hospital and the train timetable so that we could travel from Ayr to Brisbane without the need to spend any money on accommodation. My niece and I worked out that if we didn't eat on the overnight trip coming back, we would have just enough money to get a taxi home from the train station. This meant that I would need to make alternative transport arrangements to pick Mum up from the nursing home as I would not be able to afford the taxi fare to bring her home as I had originally intended, forcing me to again approach the CACP service provider for assistance even though I had decided that I wanted no further contact with them because of the earlier incident.

The second factor in my deciding to cease the community assistance was the lack of understanding they displayed towards the circumstances I was in. After telling the service provider of my situation and again asking for help to bring Mum home from respite care, I was told by the Coordinator that transport assistance was not part of the service provision agreement that I signed. When I refuted this and insisted that transportation for my mother was the main reason I sought community assistance in the first place, he told me that our transport requirements could not be considered medical appointments and his organisation does not receive money to provide 'taxi' services. The discussion became very heated when I said that there was no mention made to me that delivering Mum to the nursing home was considered a 'taxi' service which was why I had assumed they would be able to assist with bringing her home again. I then queried the amount of money his organisation receives to provide services to my mother who is a member of an identified target group and was told that it wasn't about the amount of money spent on my mother but the availability of staff to pick her up. I argued that it was all about money and if Mum was not picked up on Monday she'd have to stay put as I didn't have the money to pick her up which would cost me a further \$230 per week for her care. I then informed him of the fact that we were not middle class white Australians, we don't have ready access to years of savings to pay for emergencies like the situation I had just found myself in,

and if I did I wouldn't be asking his organisation nor anyone else for that matter for help because the truth was that he was penalising me for not being able to help myself. By this stage I was crying with frustration and anger when he then assured me that Mum would be picked up and if there were no staff available he would do it himself. Needless to say I am in the process of finding another CACP service provider and attempting to facilitate Mum's application for Queensland Transport's Taxi Subsidy Scheme.

It is this type of cultural insensitivity and lack of understanding shown in these instances that causes Indigenous people to bypass mainstream agencies in favour of Indigenous organisations when they need support, then if the Indigenous organisation cannot or will not assist, that means that the quality of care suffers, which in turn negatively effects the quality of life for those being cared for.

As a Carer I have made a personal commitment to provide support and care for another and obviously this will remain my primary concern, however if the government requires that I am also gainfully occupied with job search, study or training then they need to remove the barriers, provide more practical measures and create strategies that will encourage and improve the social and economic participation of Indigenous Carers.

I suggest that this may be achieved in the following ways:

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- The Australian government is currently trialing the Access Points Project – a one stop shop for service delivery to the frail aged and disabled. It could be adapted to create the type of Indigenous agency mentioned in the previous points and be used as a referral point for daily and living aids, offer in-home respite care, transportation assistance with

the ability to transport patients in wheelchairs, and also offer personal support via assignment of an Indigenous Case Manager for both the Carer and those being cared for;

- A publicity campaign highlighting the available services for the frail aged and disabled and how they can be accessed because people need to know what help is available.

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ATTACHMENT A

The Management Council
Brisbane Aboriginal and Islander Community Health Service

27 July, 2008

Dear Sirs and Madams,

My name is _____ I am an Indigenous community member and a full-time Carer for my mother, _____ who is suffering from the irreversible and near-complete loss of her sight, restricted mobility and has very recently been diagnosed as being in the early stages of dementia. My ability to access healthcare for her is limited because I have neither my drivers license nor access to a vehicle and I write this letter to voice my concern about your how your current policy regarding the Aboriginal and Islander Community Health Service (AICHS) patient transportation/shuttle service in not inclusive of my mother nor others in similar situations to hers, and I respectfully request that this policy be reviewed and amended if necessary.

My concern stems from an occasion where arrangements had been made for your patient transport service to take my mother and I to the Mater hospital on Wednesday 23 July 2008, however that morning I was informed by your Medical Branch Manager that because Mum had not presented to the Aboriginal and Islander Community Health Service (AICHS) for medical treatment in some time she is not regarded as being a patient and therefore not eligible to utilise this service to attend medical appointments any longer because it costs money to run that service and so it must be reserved for patients only.

I point out that Mum's status as a non-patient was never raised when we have utilised this service to attend hospital and x-ray specialist appointments on other instances. So can you clarify your criteria for assignment of the right (or should that be privilege?) to be called a patient of the Aboriginal and Islander Community Health Service? Additionally, if people (for whatever reason) have not presented to AICHS for medical or dental treatment in any set period and are no longer deemed to be patients, does that mean they are no longer eligible to access services offered by AICHS again whatsoever? But if they are, then why can't that eligibility extend to other components of AICHS service delivery such as patient transportation or are conditions and requirements going to be attached to any services offered or delivered by your organisation from now on?

However, if the advice I was given is correct, then I deem this policy to be exclusionary and discriminatory because it is penalising my mother and others like her (Indigenous frail aged and/or disabled) who do not wish to be institutionalised, are being cared for at home and who for convenience sake receive their primary health care from other health providers and therefore have not attended AICHS for a long period of time. I assume that you are aware that the cost of and lack of transport is one of the major obstacles preventing urban Aboriginal and Torres Strait Islander people from accessing healthcare. However, you should also be aware that those instances when people in my mother's situation seek health care it usually involves 'quality of life' situations that are a lot more acute and/or more complex than those of your normal clientele.

Frequently a great deal of preparation and groundwork is required to set up appointments let alone facilitate attendance to health providers. Non-attendance may well have dire repercussions but if we don't have access to a private vehicle we are forced to rely on other forms of transport (usually public) and if we don't have the money what other options are left to us? By preventing us from making use of your patient transportation service this equates to preventing better health outcomes for a section of the Indigenous community that is more often than not over-looked in favour of the more able-bodied. It can be said that we are a 'minority within a minority' and more serious consideration on ways to assist us is needed and must be promptly acted upon by those in a position to be able to do so.

We all know that taking care of family members who are frail aged or disabled is a cultural value and one of the things that we do without question and nowadays can truly be likened to being a survival tactic. Yet it troubles me that whilst both my parents have raised myself and my siblings to heed our Aboriginal cultural values, to be community-minded and to not turn our backs on those who are more disadvantaged; these very same ideals - which I assumed AICHS Brisbane had been founded upon and duly incorporated into its Constitution and service policies - seem to have been discarded in favour of saving money or making it stretch further. To my mind this equates to saying that your organisation has lost sight of how and why it was conceived and the personal and cultural ideals it was built upon and has taken on a more corporate mentality/outlook where money has gained more importance than the quality of Indigenous people's health and lives.

In stark contrast, as a grass-roots Aboriginal woman, when it became obvious to me that my mother needed to be cared for, without hesitation I voluntarily gave up both my university studies and paid employment and now we both receive the most basic income support from Centrelink - she receives her Age pension and I receive a Carer's Payment. In order to ensure bills are paid and her essentials are provided, this often means that medical appointments are often deferred until they can be afforded, as at this point in time we don't receive any other support or service from any other (mainstream or otherwise) community health agency and are truly living 'hand to mouth'. It is difficult but my caring for her at home is preferable to her being cared for by strangers in an environment that is totally impersonal and alien to her.

Both my parents were politically active in the burgeoning struggle for recognition of Indigenous rights and the establishment of culturally appropriate, community-controlled and operated welfare organisations in Brisbane during the early 1970's. Furthermore, Mum had been a patient of AICHS for some thirty-plus years, having attended your Diabetic and Podiatry Clinics as well as requiring attention for other assorted health complaints during this long period. Today she is totally reliant upon me for her day-to-day care which includes bathing, dressing, dispensing of her medication and assisting her to attend the toilet. I am also responsible for the cooking and provision of meals, washing of her laundry, and cleaning and maintenance of the home where she has lived and raised her children and grand-children for the last thirty-five years and where, but for the grace of God, she will die one day.

Even though I have had to cope with Mum's poor vision and increasing frailty her real problems started during the last six months when I become more and more troubled by her memory loss and behaviour and my suspicions were confirmed when roughly six weeks ago it was found that she was in the early stages of dementia. She was then referred to and placed on a waiting list for the Mater hospital's Neurology Clinic. However, since that initial diagnosis her mental capacity has rapidly deteriorated during the past week to the extent that she has become confused and

frightened and unaware of where she is and it became obvious that her condition urgently needed to be re-evaluated. So on Monday 21 July, I rang her usual GP only to find out that he was on leave until the following Monday, 28 July. I then contacted the Mater Specialist Clinics to see if I might be able to get her moved up the waiting list; however I was informed that while only the GP can do that, if I thought it necessary I could take her to the Mater Casualty section for assessment. I then spoke to the Casualty section and was told that a Neurologist was attached to the section every week day and if I was concerned about her condition to bring her in.

As her Carer I need to be able to make quick decisions about treatment, appointments and who to tell and how, all whilst dealing with other aspects of everyday life, so I thought it best to get her to the Mater. However I intended to wait until Mum received her Age Pension on Thursday 24 July so I would have the money to pay for the taxi fare (\$30.00 each way) from home to the Mater hospital and back again. But after discussing the situation with my cousin Maree Loftis, she suggested that as time seems to be of the essence in Mum's situation she would arrange AICHS-provided transportation to the hospital as had been done on previous occasions.

At that stage my niece _____ had already made arrangements to take Leave Without Pay from her place of employment beginning the following week on Wednesday 31 July, to come and stay with me and assist me to care for Mum, so I sent her an email (*see attached*) explaining our predicament and asking her to come home earlier. I wanted to give her enough time to arrive from Alice Springs and accompany us to the hospital as it has become physically impossible for me to take Mum anywhere by myself anymore. So the next day (Tuesday 22 July) Maree _____ finalised transportation arrangements for us to be taken to the Mater Hospital at 10:00am on Wednesday 23 July. But late Tuesday night my niece let me know that she wouldn't be able to get to Brisbane until Wednesday night and it was agreed that I should continue with arrangements already made.

Around 8:30am on Wednesday morning I received a phone call from the AICHS Patient Transport driver to say that she would be leaving soon to come and pick us up. Not long afterwards I received a second phone call, this time from the AICHS Branch Manager notifying me that even though Mum was no longer a patient of AICHS she would be taken to the hospital in this instance but in future alternative arrangements would have to be made. I agreed because I just wanted to get Mum to the hospital as soon as possible even though we were running late as Mum was resisting my hurried preparations and voicing her reluctance to go out into the drizzling rain. Then about ten minutes later the AICHS Patient Transport arrived, but by that time I was so disheartened that I lost the energy and will to go and do battle with the hospital in my bid to get Mum assessed and her condition documented and so informed the driver that I had made the decision for Mum and I to stay home.

I feel that I should make you aware of the impact of caring for a family member who is frail aged and/or disabled has had on me personally and upon my family. Time has become a very valuable commodity of which I am continually deficient in... I don't have the time to spend on myself to do little things like get a hair-cut or take the time to browse when shopping for groceries or clothes. I cannot even contemplate arranging lessons to get my drivers license even though it would make things so much easier, simply because any time spent out of the house needs to be strictly regimented and I am anxious and protective when away from her because I feel my first priority is to always be present and at my Mum's side should she need anything.

Our social contact is severely limited as outings have had to be abandoned because of the level of care that she requires and visitors are also restricted in order to preserve her privacy and dignity. I feel that this is the hardest and loneliest job that I have ever had to undertake because I am receiving only limited support from family members who are in denial and reluctant to accept the situation, and who don't keep in contact let alone visit Mum. This has left me feeling manipulated, exploited, angry and frustrated and as if I have lost control over my own life. Then comes the guilt for feeling this way because I know that I am the best person in my family to undertake this role and I couldn't live with myself if I didn't. My family is not like those found on television, we are just like many other Indigenous families who are being forced to carry the psychological and emotional burdens of intergenerational trauma and on top of that the continued social injustices perpetuated against Indigenous people in general by contemporary Australian society has left my family as fractured and as dysfunctional as they come.

This emotional roller-coaster would become soul-destroying if I allowed it to; as I have recognised that this situation can continue for years because even though her health is otherwise fine, Mum's dementia means that she will eventually lose the very essence of who she is, leaving behind just an empty shell. This insidious disease will take her memories, her intellect, her ability to communicate and her recognition of family and friends. As her children, my siblings and I will not only lose our last link to our childhood but also her knowledge of generations past and of how it was back then. Not only will we lose the chance to check our knowledge of our cultural heritage, but more importantly we will lose the chance to create more memories of her and us together. Moreover it is my love for her that forces me to witness this alteration and endure a prolonged grieving process where I mourn the disappearance of the person who was once one half the centre of my childhood universe and there is nothing I can do about it.

Furthermore, in the past when I have approached mainstream agencies/programs for assistance there doesn't seem to be the same concern for the problems and issues I am facing and my concerns are downgraded so that I become aware very quickly that my mother will not be given the same priority or understanding that their white clients receive. There seems to be an unspoken ignorance and expectation that we (Aboriginal and Torres Strait Islander people) have identified agencies/organisations which ought to deliver the services that I am seeking so therefore I should try them first before seeking assistance from mainstream agencies. So can you imagine how I felt when I received that phone call telling me that AICHS would not be able to assist my mother and I any further?

I have found recent National Bureau of Statistics data stating that 12% of the national Indigenous population are Carers, and as this is an aging population there is every chance that you or someone you know will be in the same situation as my mother, and your children may find themselves in the same position as I am. The plight of the Indigenous frail aged and disabled and their Carers need to be highlighted for it has been hidden for far too long. As an Indigenous Carer, the contribution I am making to the healthcare system, to my community and Australian society at large by caring for my mother at home ought to be recognised and supported.

As the Management Council of Brisbane's primary Indigenous healthcare provider you have the power to either alleviate the stresses that I am undergoing, or else advocate on my behalf, but how much is up to you and your conscience. What I am seeking is a promise that you will seriously consider the problems and issues raised in this letter and which are currently faced by Indigenous frail aged and disabled in your catchment area and know that they are far more widespread within our community than first realised. Those of you who know my family will

remember that my eldest brother was quadriplegic and cared for at home before passing away in 2000. The culturally-appropriate assistance that we required for his care was virtually non-existent back then, so I am seeking a promise that you will act promptly to put culturally-appropriate and supportive measures into place for other Indigenous people in the same predicament. One of the first steps I recommend you take is to review and amend your patient transport policy to allow my mother and others in similar situations to ours to use that service as this will go a long way to helping us to access essential healthcare.

I would have liked the opportunity to meet with you to personally advise you of my situation, but that is near impossible and contact by phone, e-mail or by written correspondence will have to suffice. If you wish to discuss this letter or the issues contained herein, my contact details can be found at the beginning of this letter and I would like to be kept informed of any decisions you may make in regards to this matter. However, please be aware that I am prepared to take this matter further and begin a 'complaint' campaign because of the frustratingly unsatisfactory level of service that is currently provided to Indigenous frail aged and disabled people and their Carers in the Brisbane metropolitan area. Someone needs to step up to the plate and I know that your organisation has the capacity to be both proactive and practical in regards to our plight. Please justify my faith in you.

I await your reply.

Please come home earlier

21 July 2008 12:52

Hi Kai,

I know that you have arranged to take your leave from 31/7 but is there any way that you might be able to do that sooner?

Nan's mental condition has deteriorated to the point that she is unable to make herself understood and doesn't know where she is and is scared and frightened.

Her sleeping patterns have changed significantly and I was up with her all night last night - as soon as I take her to the toilet and put her back to bed she gets up again - her confusion is worse than ever and she doesn't know where she is and seems to be getting worse very quickly! I had to sit with her until she went back to sleep last night and of course she was up with the birds this morning. I am dead on my feet at the moment and at this stage I definitely need someone else in the house at night until I can get her seen to by a specialist.

So earlier this morning I tried to rush her referral to the Neurology Clinic at Mater hospital to move her up on the waiting list but unfortunately only her GP can do that and he is on leave until next Monday, so I have arranged medical transport for us so that I can take her to the Emergency Dept at the Mater the day after tomorrow to see if that can't move things along quicker - it needs to be noted somewhere that her condition has gone down rapidly! The sooner she gets seen to, the sooner proper medication can be prescribed.... I am hoping the specialist will prescribe a magic pill to unscramble her brain and settle her down... for how long I don't know but I am hoping for a little reprieve from the onset of her dementia.

I can't do this by myself because she now needs help with bathing and dressing and going to the toilet, plus the fact that she needs to be in a wheelchair when we go out makes it doubly hard.

Aunty Mandy is to come and stay with me for a couple of months but is unable to get away just yet and you're the only other one I can rely on. I can't ask your uncles as Nan needs her privacy and you know yourself that she doesn't like strangers in the house and I refuse to put her into respite care... she is our mother and grandmother and we will be able to take care of her if we all pitch in.

So do you think that you can let me know this arvo if you are able to come back to Brisbane sooner? Like I said before, it's just until Aunty Mandy can get down here in early August sometime.