

Our people, our places and unpredictability

Maree O'Hara, Danielle Withers

Anyinginyi Health Aboriginal Corporation

Thank you to the Larrakia people for their welcome and we would like to acknowledge Larrakia people past and present.

I am Danielle Withers, Barkly Regional Eye Health Assistant and I will introduce our presentation and then hand over to Maree O'Hara, the Barkly Regional Eye Health Coordinator. We work at Anyinginyi Health Aboriginal Corporation. Anyinginyi means "belonging to us" in the main Aboriginal language here, Warumungu.

Maree named this presentation in respect of the Conference title but also because it is about the people of the Barkly region, the different towns and communities in the Barkly, and of the unpredictable journey in establishing and continuing the eye health model for this region.

The Barkly region is 323,514 sq.km – bigger than New Zealand or Italy or UK. In Australia it is bigger than Victoria + Tasmania + ACT together. The population is 8,137.

As well as Warumungu there are further 15 Aboriginal languages spoken in our area. Most Aboriginal people in this region do speak English, but not always as a first language.

Over to Maree—

I would like to take you on a bit of our journey about establishing and running the Eye Service. As the title says many of the aspects are unpredictable.

We are a community controlled Aboriginal Eye Health Service. This means that the community, and especially our Board at Anyinginyi, has a say in the way they would like our service to be which includes making appointments for optometrists and the Eye Specialist, running the clinics and doing health promotions.

This is very exciting as our community are our patients and we are not short of feedback. This means that people get the service they want, not the one others, who don't live here, think they should have.

The nine year journey of this particular model of delivery, has been one of discovery and adjustments.

A lot of assumptions were made by me (the Eye Coordinator) that were wrong, partially right and nearly right! (I am sure plenty of other eye coordinators knew more than I did when I was starting in eye health.)

I have learnt that the model we have needs to be reliable but fluid. That sounds impossible but somehow that works.

In the beginning it was obvious there were many people that needed to be seen. There was only one week of optometrists for people to be seen. There are now 17 weeks.

Our clinicians (the optometrists and the Eye Specialist) are very gracious about usually working so hard I feel we are in a horse race sometimes, galloping towards the end. Our amazing Eye Specialist agrees to work without breaks over 3.5 days. With us working beside him, we have to remember to drink sometimes!

When I started I expected predictable, orderly clinics with one person per appointment. Not in the Barkly!

The busy clinics are because we never so "no" to anyone that wants to see an optometrist. Sounds easier said than done because then we have to triple book for the one appointment sometimes. Somehow because some patients don't attend and the other patients are very good about waiting (because they understand the crazy system and why we have it) it all works.

Optometrist clinics are also unpredictable because anyone can walk in, and be seen, if they are willing to wait.

People cannot walk in on the Eye Specialist but the high level of care and number of people mean he now brings a registrar, when he can, to help with the numbers. Who knew the numbers would get so high and continue to rise??

Our community members have taught me a lot about their lifestyles and what challenges there are for many of them. This includes being a family based culture which brings with it the joys but all the sharing of multiple hardships.

This has changed my delivery of the service. It was always done with the right intent but with understanding it is even better.

Some of the wrong assumptions I made for the majority – people get sick of appointment letters (they don't), they get sick of you keep asking them to come in (they don't but will let you know sometimes subtly that the answer is no), people would not speak up if they wanted something else (they do) and an assumption I made that was dead wrong was the weather would not affect attendance.

When I moved here I was not prepared for the extremes in heat - our summers can get into the high 40 degrees and many people live in housing with little or no air conditioning. My best friend is my air conditioner! I did not also expect the brief winters – one year I think it was about two weeks long but reached around 10 degrees.

I also learnt that it was best to have an Assistant and driver that were Aboriginal but if I didn't – people understood and we all worked it out. Lucky for us we have an Aboriginal driver. He is an amazing source of knowledge. Sometimes he will just shake his head at us to let us know to leave someone alone because of personal situations (not sorry business) that we do not have a right to know about. I love this protection of privacy and for someone like me originally from Sydney who used to think they have the right to know all personal details – it has been a big adjustment but one labelled "Respect", which I am lucky to have learnt about in Aboriginal culture.

Most of our clients are from traditional Aboriginal backgrounds and continue to keep me (often via the Eye Health Assistant and driver, or directly) attuned to their needs.

This is just part of my ongoing journey but I hope it continues with such unpredictability!

Some further examples of our situations that were unpredictable:

- Some cattle stations use our service others don't. Each cattle station is different, but all appreciate the offer of the service.
- We learnt - don't book around events especially sporting – we are no competition for any footie game!
- We got to know the many challenges people have in their lives – especially other pressures from living in large numbers in houses.
- People may not always feel like coming, or can't, but don't give up, we have succeeded in 8th, 9th or 10th attempt.
- Challenge with eyes is that often there are few symptoms or people have lost their sight gradually and are resigned to the fact. If it is screening then we continue to educate people when they think nothing is wrong with their eyes that we may prevent permanent damage.
- Superstitions that are alive and well – we will take out your eye and put it on your cheek whilst we are having a look and the drops used to make the pupil bigger (so the optometrist/Eye Specialist can see the back of the eye better) will blind you.

- To keep the eye specialist and optometrist services busy we have needed to double/triple/quadruple book one appointment.
- Good stuff that has evolved (unknown in the beginning) – free sunglasses, cheap reading/distance glasses, hand delivered letters, being picked up at appointment times, flexibility so that no matter what is happening in your life you can be seen. Graciousness and patience of people understanding what the service is trying to do and willingness to wait sometimes.
- Different communities have different challenges. We work from Community Health Centres and some cannot supply transport to vision clinics at all times. That is hard and less people are seen.
- Be aware of sorry business – at least a week when you should not go to the grieving community.
- Unpredictably to an ex Sydney sider - “Wet” and “Dry” seasons – basically travel in the dry but not the “Wet”. The “Wet” can cut off communities for weeks.
- Accommodation – Health Centres can rarely supply accommodation so we are then left with Government Business areas and local Council housing. The last two were not always available either.

Worst scenario – at one place there was no health centre housing, no government business housing, no local Council housing – only one caravan in whole town left – gave it to the optometrist and pleaded to stay at someone’s place who I knew.

Another time a cattle station kindly put us up for nothing until they asked the optometrist if she could look at their dog, goat and horse with eye problems. She did!

- Be a good scout and always be prepared that helps with unpredictability. The optometrist and I went for a day trip to Elliott (2.5 hours away). Whilst there a cyanide truck overturned on the highway and we couldn’t get back. Several hundred people were stranded at a road house (I knew the owners and begged a bed for the optometrist and myself). We felt we owed the roadhouse as they would not accept payment so we waited on tables that night (for free). We slept in our clothes that night and into the next day when we got through.
- When you have relationships with people in administration and health they may leave and the next person does not operate the same way (start all over again). Makes you very grateful to the helpful people that you have around you.
- Most of our optometrists who go to the communities come from the College of Optometry and some are very enthusiastic. I had one optometrist talking to a patient and then the patient walked off (to go to lunch). I then came around the corner and asked where the patient was as she was not finished. The optometrist started to run down the street chasing the patient. I had to run down the street to chase the optometrist to tell her not to chase a patient!
- This was not unpredictable but essential to enforce - continuity and trust is everything so the trust you establish is essential and you must do what you say and follow up as you say you will. People should be free to ring or come in if they are worried about anything.
- Being part of a health organisation we do have knowledge of the multiple challenges people have who have chronic diseases. They may be on dialysis, have diabetes, blood pressure problems and dietary challenges. Many are overwhelmed by the number of appointment and blood tests that need to be done. We need to work with other areas in their lives so it is all manageable for the patient. We also have a very good relationship with the renal unit who work with us in assisting people to get to appointments.
- In the same way, being aware of changing circumstances and the need for coordination of many services. Sounds obvious but changing circumstances can cover a wide range of situations.

- Recently we had a young patient who needed urgent eye surgery. With the assistance of many areas of health, an escort was supplied by Anyinginyi who was fantastic in a staying with her for a whole week, allowing that girl to get the urgent surgery she needed. She did not have family that could help her and that exercise needed the understanding of three organisations, two specialists, about a dozen nurses and various administration staff. Well done everybody. This was not a predictable situation but one that needed a quick coordinated response. Also on the basis of this, Anyinginyi has agreed to supply escorts again for those in need.
- Who you meet? Networking is always valuable but what is special and sometimes surprising is when you meet someone who can be of immense support with people, especially when that level of support has not existed before. The cliché that nobody is irreplaceable I don't think is true of many extremely effective workers.
- Unpredictable and surprising is the level of funding – it has not changed in many years and means that to do our job with the increase of numbers and severity of eye diseases – we are now supported by a charity (thank you to Fred Hollows Foundation).
- Unpredictable is the level of enjoyment I still get in seeing people maintaining their eyesight – especially first pair of glasses and first cataract operation. What a kick to see their amazed look on their faces!
- The stories we all have – hunters (male and female) who haven't been able to hunt for years and then having a cataract operation which means they can hunt again, artists who haven't been able to see and then can go back to painting again. A personal favourite is drivers who get back good vision and continue to drive but more safely!
- Geography is always the challenge. Many people live in communities but also may move around. Finding people is an interesting unpredictable challenge always – we call ourselves (the three of us) the best Detective Agency in the Barkly. Mind you we have a lot of people we can ask to find out information.
- The smallest things are unpredictable in this job. We have glasses that are part of the subsidised scheme for glasses for Aboriginal people. We have a limited but good selection. Do you think you know what people are going to pick? Only sometimes and not in the majority of times! You only hope they still like them when they get them.
- Primary School and High School screenings – I do once a year whereby three of us registered nurses test Primary and High School children for different eye measurements, including Trachoma. Our results (surprising to me) are consistently that 30% of children need further testing by an optometrist. This is equal to other areas in the NT.
- A few years ago a very nice gentleman from AMSANT (Aboriginal Medical Services of the NT) advised me to put up pictures in my office so people could place me in a personal way. Being very private, and having never done this in 25 years – I was not sure. However he was right! People do respond well here to looking at your family pictures and often asking about your life. This has helped a lot in establishing/maintaining communication.
- People are unpredictable! Patients surprise you with what they do and say, and so do other staff. As our newish Diabetic Educator said "I studied every statistic about the Barkly before I came and thought I was thoroughly prepared but I was reminded (when I got there) statistics are only one aspect and people's realities are very different and are the whole story."
- Aren't we lucky that this job is so interesting but this leads to the recommendation that the Rural Health Alliance has requested. Our recommendation is "That Outreach and Regional Eye Care Coordination programs and positions are reasonably and reliably funded across Australia, to

enable maximum impact of eye services and best outcomes for patients, especially Aboriginal and Torres Strait Islander people.”

- Fred Hollows Foundation fully funds Danielle’s position and this has enabled us (as a two women team) to see 1149 people with the optometrists last year and 424 people with the Eye Specialist.
- As the Eye Specialist says you cannot lose your life with your eyes but you can lose your lifestyle. Let the funding reflect the huge impact a loss of vision can make on people’s lives.

Presenters

Maree O’Hara has been the Barkly Regional Eye Coordinator at Anyinginyi Health Aboriginal Corporation in Tennant Creek N.T. for the last 9 years. She organises the optometrist and ophthalmologist clinics in the Barkly region, and with her assistant facilitates these clinics. Her role also involves Health Promotion and a recent collaboration with Fred Hollows Foundation has resulted in a DVD “Looking Better” now available on request. She has worked in Aboriginal health, education and employment for the last 28 years. She has worked in these areas in not only Tennant Creek but Thursday Island, Normanton, Mount Isa, Tennant Creek, Weipa and Borroloola. She works in partnership with the Fred Hollows Foundation, Brien Holden Vision Institute, Alice Springs Hospital Eye Clinic and OPSM. She was nominated in 2012 for an Australia Day award for her work in Eye Health.

Danielle Withers has been with the Eye Health Program for five months as the Eye Health Assistant. She comes from Townsville and this is her first position in eye health. She has worked in Aboriginal education and retail. Her last place she worked was at Maningrida. She is enjoying working in eye health and learning more about Aboriginal culture.