

Looking back. Looking forward.

What to take with us?

What to leave behind?

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Please note: There is some additional material provided in this written version of my talk. I have included sections which time did not permit me to include verbally on the day. I have also added a list of the relevant references.

I am aware that in my talk and here in the written form, I am using and making comments about issues that relate to Indigenous people, especially in relation to Indigenous people living in remote communities. I am conscious that as a non-Indigenous person, it may not be my place to say some of the things that I said, or I have not said in an appropriate manner. I hope that anything I have said does not cause offence and is appropriate.

In my talk, I have drawn extensively on the words written and said by a number of key people such as Andrea Mason and Kim McRae, Fred Chaney, Gemma Carey, Lorna Hallahan, Richard Flannigan and Scott Amery. I have also drawn on the findings of two studies conducted by the University of Melbourne and Flinders University. I am indebted to the contribution that these people have made to my thinking and trust and hope that I have honestly and accurately reflected their points of view.

I particularly wish to thank and acknowledge the work of the NPY Women's Council and the Anangu people of the APY Lands which has helped me so much in my thinking of these issues. I commend to you their most recent report, "Walykumunu Nyinaratjaku: To live a good life" which Kim McRae spoke to on the day of the conference. This latest work addresses the question of what makes a good life for Aboriginal people with a disability from the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Lands. The project was a collaboration between NPYWC, the Faculty of Health Sciences, University of Sydney; the Poche Centre for Indigenous Health and Wellbeing, Northern Territory; and the Centre for Remote Health, a joint centre of Flinders University and Charles Darwin University.

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I want to begin by acknowledging the Larrakia people on whose land I am gifted to live on and where we gather today. I want to pay my respects to their elders past and present and to their future elders. I also wish to acknowledge all Aboriginal people here today.

I also want to acknowledge both retiring NDS CEO, Ken Baker and new CEO, Chris Tanti. We are most appreciative of all that you have done in your role, Ken and thank you. And Chris we look forward to working with you.

I want to thank the NDS for this invitation to share today.

I have such a strong sense that we are living through really important times here in the Territory.

That in years to come we will look back on these times and say that we were around then.

And I sense that we are either going to be incredibly proud for what we lived through or very sad about what we allowed to happen!

I also have a sense that it is as if all of us are being asked – individually and together – to listen to and to respond to these times in a new way.

For a few moments today, I want to stop and reflect on where we are at this time, this moment, this place.

The case for the development of the NDIS put by the Productivity Commission in 2011 was underpinned by evidence that Australian disability services were underfunded, inflexible, fragmented and built around the needs of the service system, rather than those of individuals.

The previous system was seen to be a patch work of block funded and procured services which was inefficient, ineffective and inequitable. The funding and organising of disability services was seen to be complex with gaps and overlap in state and territory and federal responsibilities.

Proponents argued that people with disabilities had little choice and control over services they could access, which were largely being determined by professionals, or what was locally available, or what various levels of governments provided. These issues raised concerns related to equity of access to services and support that were determined by individual circumstances.

Five years into the scheme it is questionable if things are any better!

At this time when we are talking about personalization, about individual plans and a market approach to the provision of services to people with a disability we have been hearing on our radios the daily news of the findings of the Royal Commission into the banking sector – of the unethical selling of an insurance plan to a young man with Downs Syndrome; the selling of mobile phone plans to people living in remote communities without mobile phone access; and the unscrupulous selling of funeral plans to people with limited financial literacy.

And perhaps, like me, you pause for a moment, and wonder if the “selling” of these “plans” to people with a disability living in our remote communities is any different to some of the exchanges that are going on in the name of the NDIS!

This year I was fortunate to attend the annual Garma Festival on the land of the Gumuj people. I had wanted to go this festival for over a decade, so it was an honour to be among the two thousand or so Ballanders that gathered at Garma.

The theme of this year's "Garma" was "truth telling". And in the spirit of this year's Garma, I want to use this opportunity to speak from a place of "truth". I want to use this opportunity to speak from that place – not critically of any individual or agency or political party, but from a place of calling it for what it is.

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"What is it about the original NDIS vision that we want to carry forth?", and

"What is it that we need to leave behind?"

And in answering these questions, I want to continue on from Ken Baker's talk – *"There is more to life than the NDIS"*. I want to talk broadly about social inclusion. But I am going to keep coming back to the NDIS, because it is such an integral reform in our lives. Indeed "social inclusion" is the primary or central tenet on which the NDIS needs to be held to account.

Because at the end of the day, after all the problems we have had with the portal; and all the planning reviews; after all the NDIA briefings and forums, and meetings with the Office of Disability... the primary question comes down to – "Are Territorians with a disability more included in the everyday life here in the Territory?"

And I am going to suggest that we will only find a way forward for social inclusion here in the NT when we are able to truly find a way which is led by culture. And further to this, I want to suggest that a "culture led" response has significant relevance to all people, Indigenous and non-Indigenous!

Yesterday some of us had the opportunity to meet and talk with Chris Tanti and to brief him about the state of the NDIS here in the NT. And we began by saying how hard it is to get any sense of how the NDIS is rolling out across the Territory, and in particular in remote communities, because there is such limited data available anywhere in the country.

The only real data that the NDIA is making available is in relationship to the number of plans and the draw down on those plans. And we know that there are many agencies that still have funds to draw down from the past eighteen months! It's not only a bit of a mess but the agency has not given any commitment to providing good data. Nor in any part of the country am I aware of any evidence based external analysis of the quality of these plans, nor any review of what is coming from these plans – outputs or outcomes.

But we know from Kim McRae and her team from the NPY Women's Council that the implementation of the NDIS on the APY Lands has been incredibly problematic with only a dozen or so plans actually approved and next to no services provided. And all that after five years.

Last year, Kim's boss, Andrea Mason, CEO of the NPY Women's Council gave the Kenneth Jenkins Oration at the NDS CEO Meeting in Sydney. It was an important speech that I think has not been given the respect that it is due.

In her speech Andrea told us some things that we need to take with us, that if we want to successfully implement the NDIS among her people, then there are some things we will need to take with us on our journey!

Andrea's spoke of what she called an "Aboriginal and Torres Strait Islander governance and business operating rhythm" which is lived by her people intimately. Andrea said she is "led by women who... live their identity through the foundations of this rhythm, country, family, language and law/lore." She spoke of how this rhythm owns them and how they own this rhythm.

At its heart, Andrea said, this ... "governance and business operating rhythm has set structures for social, economic, cultural and political order and its foundations has a bias that leans towards and elevates cultural embrace."

Specifically, in relation to the NDIS, Andrea suggested that engagement should occur at a pace in time with this rhythm, defined by Anangu properties and processes rather than in accordance with Government deadlines.

I have been privileged to have spent some time on the Anangu Pitjantjatjara Yankunytjara (APY) lands in South Australia, and I learnt very quickly of the need to work within this rhythm. I learnt too that to be effective on the lands, I needed to leave behind what I thought was important back in Adelaide and instead be directed by Anangu.

In September 2014, the NPY Women's Council published the Final Report of a consultative project entitled *"Assisting Indigenous Australians in the Anangu Pitjantjatjara Yankunytjara (APY) Lands to Benefit from the National Disability Scheme (NDIS)"*.

In the introduction of this report, the authors noted that it is important to bear in mind that:

The life Anangu choose to live is not necessarily the life that mainstream service providers would advocate. For Anangu the opportunity to live on Country among family members overrides the desire for less crowded, more hygienic living conditions, access to facilities and even an increased quality of medical and day-to day care."

In the same vein, Andrea Mason has suggested that "a remote Aboriginal lens should be applied to the 'reasonable and necessary' clause".

The NDIS needs...

...to recognize that an Aboriginal person living in a remote area will have life goals that are very different, and don't necessarily 'fit' NDIS's expectation. For example, if an Aboriginal person in a remote community has goals that align to their operating rhythm, including family, going bush (hunting/bush tucker collecting), practicing lore – art/music/dance, language, cultural identity, traditional healing, then these are valid goals that should be funded in their plan and assessed against the operating rhythm.

...Yes the goals for Aboriginal people living in the desert might be completely different from what NDIS are used to funding, but they are no less important.

The authors of the 2014 consultation noted that:

On the Lands people often sleep on the ground or on mattresses on concrete verandas so the provision of beds and swags is actually considered reasonable and necessary to support people who have a disability. Bedding is frequently burnt or abandoned for cultural reasons, or mislaid or stolen. The combination of swags and bedding is particularly useful as Anangu regularly move between communities. Having your basic needs met like access to food, swags, blankets and clothing, becomes what is most important.

But these items are not considered “reasonable and necessary” by the NDIA.

As Andrea continued in her NDS Oration:

Living standards on the APY lands are much lower than the rest of Australia due to a whole range of factors including the cost of living, lack of education, job and opportunities.

As a result, it is not unusual for families to be struggling financially or to be preoccupied with trying to ensure the basic necessities of life are met

Individuals and families from the NPY Lands have become reluctant NDIS participants because they cannot access “proper help’ through their NDIS funding.

‘Proper help’ requires listening to the needs and concerns of the family and addressing the most urgent of those needs. For example, if there is not enough food in the house helping people to access Emergency Relief Funding or providing food some other way is of the highest priority: it is not appropriate to say to a family that doesn’t have enough food you cannot help. It would also not be reasonable to expect a family in that situation to be interested in talking about what the NDIS can do to support the family member with a disability.

“Proper help”, to Anangu involves the development of a trusting relationship with workers, involving repeated supportive visits to family over time. Developing a supportive relationship is likely to involve that worker helping the family with issues that may appear at best peripherally related to the child’s disability, but which responds to the family’s expressed needs.

“Proper help” is about relationship.

“Proper help” is about respect for the traditional operating rhythm.

“Proper help” is about seeing the whole person and their community and not what disables them.

“Proper help” is about basic rights such as food and shelter and bedding.

“Proper help” is about reciprocity and mutuality.

'Proper help' was not something that was found to have taken place in the Barkley Trial.

According to the Flinders University Evaluation, while attempts were made over time to adapt NDIS processes to local need, by the end of the evaluation period it was still felt that both the approach and implementation of the NDIS trial in the Barkley had been ineffective.

The NDIS was not perceived to have adapted sufficiently to address the specific needs of the Barkly region. Nor was the model deemed to be culturally sensitive and appropriate to remote needs and service delivery.

Overall, the Flinders University researchers found that in the Barkly region participants were shown to have particularly limited outcomes under the NDIS. While wellbeing had improved for some families and carers, the majority of NDIS participants did not experience greater wellbeing because of the NDIS. In general, there was a lack of adequate funding for transport, respite, support coordination and skill development.

According to the researchers "choice and control" remained an almost theoretical concept and these processes were challenged by the virtual absence of a viable disability support market.

Concerns about choice and control was not something unique to the Barkley Trial. In 2017 the University of Melbourne undertook an evaluation of the Barwon Trial site near Geelong which is considered to be a semi urban/regional location. And as we look at these findings, I want you to see them through the eyes of an NDIS participant living in a remote community in Northern Australia.

The study "*Choice Control and the NDIS. Service Users' perspectives on having choice and control in the National Disability Scheme*" examined the progress of the NDIS towards addressing the issues identified in disability services before it was introduced:

- whether it is giving people with disabilities more choice and control over their care;
- whether it is making the funding and organising of disability services less complex and more efficient; and
- whether it is promoting equity of access to services and support.

In some cases, especially in regional areas or where people had specific needs that could not be met by local service providers, service users had limited choice over what was available for them to purchase with their funding package.

A significant portion of their funding was being consumed by services travelling to them, or them travelling to access services.

Where their preferred options were unavailable, participants risked losing funding altogether because not purchasing services, equipment and support set out in plans was taken by planners as evidence that these supports were unnecessary.

A lot of families of people with disabilities did not really seem to know actually what they wanted to do because they were not practiced at making choices or making real choices. They were practiced at making choices from what was available, but not necessarily saying, 'I don't

like anything that you've got available for me, this is what I want because that's what will make a difference to my quality of life.'

The authors of the report suggested that:

...differing emphasis placed on the value of choice, and potential to exercise choice, is likely to undermine the potential for equity of outcomes across NDIS. The circumstances for people living with disability, particularly for those also living on low incomes and in rural areas, means that they may not be practiced in contemplating and asserting notions of choice for different reasons, including a lack of fully operational markets leaving some people with few, or no, services to choose from.

Many participants expressed concerns that the views of people with disabilities, their families and carers were often overlooked in planning processes, that communication processes and messages in the NDIS were inconsistent, and that some people with disabilities were disadvantaged because they could not fully understand the system, its costs and its administrative requirements.

Many participants also described challenges accessing and understanding the huge volume of information surrounding the NDIS.

In relation to equity, the authors of this study suggested that:

Insufficient attention was being paid to promoting equity of outcomes among service users with diverse needs and circumstances. Factors that are well-recognised in driving inequality – household income, education, residential location and household structure – remained critical in filtering opportunities and capacities for service users and their carers to have choice and control in accessing services and resources under the NDIS.

In some interviews, they noted, there were suggestions that participants' socioeconomic status played a part in shaping their expectations of the scheme, as well as their relationship with care planners and service providers. For example, people living in communities where poverty is a common experience may compare their situations with those of others around them and express satisfaction if basic needs are being met. This was evident in many interviews where participants expressed gratitude for any help they received under the scheme even when it fell short of what they had hoped, or they were uncertain about what they could ask for.

We would have no problem with concurring with many of these findings from our experience here in the NT. Indeed, it is significant that these findings are from a region that covers only a very small section of the state of Victoria and yet the Barkley Trial operated across a region the size of the entire state of Victoria! We would also expect that many of the participants in the Barwon Trial speak English as their first language, have some functional numeracy and literacy skills as well as have access to computers with internet access! We also might expect that they were able to exercise choice and control from an established disability service "market" as opposed to what we know doesn't exist in the Barkley.

Gemma Carey from the Centre for Public Research at the University of NSW in Canberra has been at the forefront of monitoring the transition of governments around the world to personalised care and market-based approaches to public service provision.

We have seen shifts in many industrialised countries away from collective social welfare provision in favour of markets and 'self-directed care. Individuals are placed in control of their own revive needs by leveraging market-mechanisms. Markets are a form of what is known as particularism in welfare: particularism aims to address differences between individuals on the basis of diversity of needs, moral frameworks and social expectations, through a non-institutional model.¹

The move towards public sector markets has been driven by the spread of neo classical economic ideas about the free market couched in terms of citizen choice and empowerment. The notion is that unfettered markets will self-regulate to create efficiency and support growth and prosperity and should therefore be used whenever possible. It is argued that enhancing choice and control via personalisation will be achieved through financial devolution, making people eligible for state funding aware of how much money is available and then giving them more control over how that money is spent².

Carey argues that across the political spectrum 'choice and control' of public sector services is seen as a way to gain economic efficiency, while enabling citizens to have a more empowered relationship with the state... "personalisation through markets has been called the cornerstone of modernisation of public services."

According to Carey and her colleagues, the shift to "public sector markets" is highly controversial and contested. When it comes to accessing whether competition and diversity driven via market mechanisms have improved quality, the evidence is sparse and contradictory.

Lorna Hallahan argues that "choice and control" is a weak mantra, too vulnerable to further deterioration.

Choice and control ... might be a groovy advertising slogan for the NDIS but it is so under-theorised and under examined that it becomes what is called a hollow signifier... a clear empty vessel into which anyone can pour any dangerously seductive rubbish they want.

I have known Associate Professor Lorna Hallahan for over twenty years and was pleased to catch up with her recently when she was one of the keynote speakers at the Anglicare Australia National Conference.

Among other things, Lorna is the Head of Social Work at Flinders University; a former member of the NDIS National Advisory Committee, including co-chairing of the Expert Advisory group on Quality and Safeguards, and from 2013 was one of the four chief investigators on the Evaluation of the Trial of the NDIS.

Lorna also is a person with a significant disability.

¹ Carey and Crammond 2014, cited in Carey et al 2018.

² Needham and Glasby, 2015; cited in Carey et al, 2018.

In a recent speech, Lorna acknowledged that whilst many people with disability are discovering more flexibility through the NDIS, this is not a widespread consequence of the changes.

There is almost universal frustration with the agency interface and the transactions required to 'get onto the scheme'... Way too many people are reporting high levels of interrogation, surveillance of their living arrangements and informal supports...

Lorna asks the question, "How did a commitment to individualisation of funding and personalisation of services, end up being so flatline and anodyne?" She asks if it "is too late to rescue genuine personalisation?"

Lorna argues that one of the consequences of the design of the new system, which must demonstrate a commitment to ensuring that public money is spent with efficiency, sustainability and equity, is to ensure that 'some don't get more than they deserve'

The old deserving poor hack. It is a deep default within welfare systems such as ours, even when we try and transform it into a welfare market. It is based on lofty public virtues such as social responsibility, fairness and thrift. ...(But) it's practice can quickly morph into suspicion of claimants, rigidity of eligibility criteria, shallow decision making, 'speed under performance' pressure, all manner of distancing tactics (the best of which is seeing a person only a representative of a class), excessive surveillance, and accountability of users rather than providers.

Hallahan calls this '*governmentality*' - the way governments try to produce the citizen best suited to fulfil those governments policies and the organised practices (mentalities, rationalities, and techniques) through which we are governed.

The danger comes about when...

People take on the subject-state that is summed up in those eligibility tests. And so they start to second guess what might be in the mind of the planner (who by the way is not really a planner but a rationed or apportioned) and in that way reduce their hopes into 'reasonable claims', often in my view way below the bar. And all in an environment where the system increasingly communicates a view that they (the claimant) are trying to game the system and get more than they deserve.

"Control", Lorna Hallahan suggests, "has reverted to a rationing system and choice has become the way in which we style ourselves to fit" where "we turn into a creature of the system of funding distribution rather than a creator along with those close to us, of our own life story".

Lorna believes that one of the possible outcomes of such an approach is that you have "to present as pathetic in order to maximize your package and in the process you feel humiliated.... everyone is in a lather of proving how impaired they are. And certain professionals are making a lot of money helping people to demonstrate their lack of capabilities."

The consequences of this for many people can be dire:

"It is fundamentally and predictably difficult for a person who is living with significant lifelong impairment... to free themselves from the terrain of low expectations and hopelessness via a process of rendering themselves needy, even pathetic. Their goals of getting the supports they need in order to flourish turns into getting the impairment

points they need to get into the system. People are already buried in a system that has so often depleted their strengths, because we have come to believe that our claims will be viewed as immodest and over-reaching; or that our imaginings of a different life are stupid and unsustainable.”

Lorna suggests that in order for us to go forward:

We have to go back to a fresh starting point. One of optimism, of respect and of releasing and building capability. When this happens we can see that people front the system with a life-expanding vision, grounding their self-concept (or in the case of those with profound impairments) those who love them believing that a small life doesn't have to be deprived and meaningless, in short, we start by believing and then acting on the belief that we are here to support the person to strive for meaning and purpose in their lives, as well as joy and connection and self-respect. This is the way to have goals.

At Garma this year, I was very aware that we were gathering on the land of the first place in the nation that the NDIS was rolled out fully in a remote location outside any trial. It is perhaps worth noting that it commenced on 1 January at a time that one would suggest was not only out of 'sync' with the governance of the people but also the weather! And as I sat and listened to the different speakers, I kept wondering what issues like sovereignty, the *makarrata* and the Uluru Statement had to do with the social inclusion of people with disabilities.

One of the first elders that spoke to us was the leader of the Gumatj Clan of the Yolngu people, Galarrwuy Yuninpingu. In 2016 Galarrwuy Yuninpingu wrote an important article in *The Monthly*:

What Aboriginal people ask is that the modern world now makes the sacrifices necessary to give us a real future. To relax its grip on us. To let us breathe, to let us be freed of the determined control exerted on us to make us like you. And you should take that a step further and recognise us for who we are, and not who you want us to be. Let us be who we are - Aboriginal people in the modern world - and be proud of us. Acknowledge that we have survived the worst that the past has thrown at us, we're here with our songs, our ceremonies, our land, our language and our people - our full identity. What a gift this is that we give you, if you choose to accept us in a meaningful way.

Fred Chaney quoted this important article in the Cranlana Oration that he delivered in June this year. Fred was also at Garma this year and I appreciated the opportunity to talk with him. For those of you unaware of his reputation, Fred Chaney is a former Western Australian politician who served as deputy leader of the Liberal Party from 1989 to 1990 and as a minister in the Fraser Government. In January 2014, Fred was awarded the Senior Australian of the Year.

In 2014 at the 11th ANU Reconciliation Lecture, Chaney said:

There is much in Australia today to suggest that we are not very interested in allowing room for Indigenous culture to continue to be part of our national fabric. Whatever lip service we offer the world's oldest living cultures, the clear message from our actions is that our main concern is to bring Indigenous individuals into full employment of their rights and duties as Australian citizens. There is no clear message that we

understand and value these cultures as part of our nation. There is no indication from our actions that we will preserve sufficient space for the Yolngu, the Nyungar and so on to retain collective communities that still observe practices close to those of pre-settlement cultures, the policies of successive governments seen designed to strangle them.

At Garma this year, Fred Chaney took bureaucrats to task over what he described as a series of policy decisions that had driven people living in remote communities further into poverty.

Fred outlined these arguments in his Cranlana Oration,

These changes remove Aboriginal agency, the right and capacity to make their own decisions on matters affecting their lives. They diminish both Aboriginal authority and engagement. They deny a right to be different. They serve to strip away the dignity of those who suffer the humiliation and despair of being characterised as not only welfare dependent but without any social value within their own communities and territories.

Since the intervention in the NT the pattern has been to drive change through punishment and control with existing positives being undermined by externally imposed changes. That results in poverty despair and rebellion rather than progress.

“This is really no more than common sense”, according to Chaney. “Wicked problems, problems affecting people that are multi factorial such as health, education, social order, and employment, do not admit to solutions which do not involve the active participation of those involved”.

Chaney calls us to acknowledge and recognise our obligations in the name of reciprocity:

It is distressing to see the superficial recognition of traditional culture through the obligatory photo opportunities that Prime Ministers and other leading politicians seek out when visiting the more traditional communities in remote Australia. What is not recognised by those politicians who receive the respect and ceremonial hospitality offered to them, is that traditional culture requires of them a degree of reciprocity and a giving of something of value in return to those who have offered their hospitality and courtesy. It is inevitably a one-way street, with the politicians receiving the plaudits and kudos of public recognition, while the communities wait for some reciprocal action on the part of the government in support of their local ambitions.

Quoting the Australian Productivity Commission, Chaney notes that “Governments need to adjust their structures and processes and build the capabilities of their staff to implement more localised (including place-based) approaches:

For the last five Parliaments, despite government rhetoric to the contrary, remote communities have been subjected to top down government knows best policies and administration that has reduced Aboriginal agency, used punishment and the removal of sustaining programs to achieve government ends, removed the base of local administration and encouraged dysfunction.

According to Chaney, we are seeing, an ever-increasing centralisation of top down command and control type decision making rather than a decentralised and regional approach which provides for place-based decision making in partnership with local communities.

“These changes imposed by governments,” Chaney says, “do not relax the grip of external authorities. They do not permit Aboriginal people to breathe”.

In the Cranlana Oration, Chaney listed the externally driven changes imposed on remote communities over recent years which have contributed to despair and dysfunction. These include the abolition of ATSIC; the NT Intervention: the NT local government reform; and the abolition of CDEP.

I would throw the implementation of the NDIS into this mix as yet another top down without us example of government intervention.

When I put this to Michael Lye, Deputy Secretary, Department of Social Services, at Garma this year he gave examples of the community connectors that are being ‘trialled’ in remote communities across Australia. It has been impossible, however, despite repeated attempts, to get any information on these programs. My concern is that rather than working with communities to develop a bottom up approach, these connectors have been engaged with no other mandate than to engage communities in the implementation of the top down model designed in and for Geelong!

I want to turn to the work of Scott Avery and the First Peoples Disability Network.

Avery in his recently released landmark book, *“Culture is Inclusion”* proposes a First Peoples Cultural Model of Disability and Inclusion which sees culture as an affirming and inclusive force in the health and wellbeing of First Peoples with disability.

Avery’s Cultural Model of Disability and Inclusion is different from both the medical and social deficit models of disability:

Both the medical and social models frame disability as a deficit against perceived optimum human condition. The medical model presents disability as a deficit in bio-medical condition and aims to mitigate the adverse bio-medical impact of what is perceived as a negative cognition, with the utopian end point is cure. The social model of disability presents the deficit in terms of the environment, be it the built or social environment. The goal of the social model is to overcome the defects in the environment, and its utopian end-point is to accommodate people within a fully inclusive community in which negativity does not exist.

The First Peoples Cultural Disability and Inclusion model presents a philosophically different approach based on the premise that within Aboriginal culture there is no word for disability. It is based on a notion that no one is excluded, even a notion that there is no such thing as disability. It is not a negative deficit model that requires a cure or accommodation! It is inherently ‘inclusive’.

The First Peoples model, Avery argues, is the only model that seeks to improve the human condition through positive affirmation, as distinct to merely negating the adverse impact of difference.

Avery also points out that there is a risk of over-romanticizing the culture of inclusion. I refer you back to the 2014 the NPY Women’s Council study which identified many reasons why disability was not recognized by Anangu.

It is due to these factors that as both Andrea Mason and Scott Avery point out, we would expect that not only is actual numbers of Aboriginal people with disability to be understated but also under represented in accessing disability services, where they exist.

According to Avery:

Aboriginal and Torres Strait Islander people with disability still walk in ‘two worlds’; their Aboriginal and non-Aboriginal world. The numbers and the narratives... show that on balance with Aboriginal and Torres Strait Islander people with disability experience the worst of both worlds, in that their cultural normalising of disability means that they do not access services at the level they need, yet they still suffer from the ill effects of negative stereotyping, labelling and discrimination. Aboriginal and Torres Strait Islander people with disability face a conundrum in trying to improve their position – in order to access the services they need in a non-cultural model, they effectively have to disable themselves, a concept that is antithetical to their cultural beliefs.

In 1991, Lester Bostock, the founding elder of the First Peoples Disability Network, publicly introduced the concept of “double disadvantage” and how it relates to Aboriginal people with a disability. At around the same time the concept of “Intersectionality” was devised by the critical race theorist Kimberle Crenshaw to explain the effect of race and gender upon the incidence and impact of family violence against African American women. Crenshaw observations of intersectionality showed that an explanation of race or gender in isolation from each other did not fully describe the experiences of African American women.

This same concept of “Intersectionality” has been taken up Scott Avery. As people with identities traversing two marginalized groups, Aboriginal people with disability experience both racially based discrimination (racism) and disability related discrimination (ableism).

Avery writes:

Intersectional discrimination is not a point in time concept. The detrimental consequences of intersectional discrimination at one point in life can be life long, as it increases the likelihood of being exposed to future experiences of exclusion and discrimination. The inequality experienced by Aboriginal and Torres Strait Islander people with disability accumulates over the course of their lives. Even before they are born, the social circumstances into which Aboriginal and Torres Strait Islander people are born can add to the burden of disability. The impact of undetected and unsupported disability in their early childhood carries forward into the schooling years. This compounds into greater inequalities in later life, effectively placing them on a “matriculation pathway into prison”.

The notions of “double disability” and “intersectionality” help us to appreciate that we cannot address issues of exclusion and discrimination without an appreciation of culture. And if as we have proposed the NDIS is to be held to account in relation to the extent to which it enable social inclusion, then it cannot do this without a deeply embedded notion of culture.

How does such an approach translate into policy and practice? Avery recognises that the status of research is not sufficiently advanced to be prescriptive. But it is presented as a vision and direction for future research.

Besides Amery's own research as outlined in *"Culture is Inclusion"*, there are a number of other significant efforts that have already begun to fill this void. *"Walykumunu Nyinaratjaku: To live a good life"* is a very recent publication from the NPY Women's Council which asked the question of what makes a good life for Aboriginal people with a disability from the Ngaanyatjarra, Pitjantjatjara and Yankunytjatjara (NPY) Lands. Inspired by the 1994-5 report, *"They might have to drag me like a bullock"*, which told of the experience of older people on NPY Lands, this most recent report asks how Anangu and Yarnangu with disabilities perceive a good life and want to live their lives.

This has never before been documented and the findings are significant:

Anangu and Yarnangu with a disability want to live in their communities, on the NPY Lands with family. This is more important than the quality of the care they receive, or the availability of services. It is important despite the difficulties they encounter in accessing basic daily amenities including food, clothing and bedding, which remain a major priority for people living in community.

For those Anangu and Yarnangu with a disability who are living in community, a good life also means being included and participating in cultural, family and community activities such as arts and crafts, bush trips, bush medicine, music, television, sport, socialising, spiritual life and shopping.

The authors of this report argue that people living in the remote NPY Lands are a long way from receiving the person centred services that underlie the NDIS philosophy. They provide many examples which illustrate that Anangu and Yarnangu have little choice or control over the disability supports and services that they receive.

They note that the NDIA works on the assumption that all people with a disability start from a baseline where these basic needs are met every day, that everyone has a moderate level of literacy, and that a wide range of services is universally available.

The findings of this study make it clear that on the NPY Lands, this assumption is false.

For Anangu and Yarnangu, the need for basic resources (food, bedding and basic goods) must be satisfied first. Only then can people consider the more complex and less immediately urgent needs that result directly from their disability or the disability of someone they are caring for. People on the Lands speak English as a third or fourth language and many have limited literacy. For this reason, they find it difficult to negotiate bureaucratic systems without extensive individual advocacy.

When a small group of us met with Chris Tanti yesterday, he asked us what we wanted from him as the new leader of the NDS. The answer came easily to me. We need to reimagine what the NDIS looks like. NDIS Mark I is severely flawed. Its deficit, transactional, top down, market driven approach is clearly problematic, not only in the remote communities of Australia but nationwide. We need a leader that can help us to believe in and create a new way forward who has the capacity to bring NDIS Mark II into fruition. And if we can get it right in the remote communities of Australia then the rest of the country will follow suit.

I want to propose that the Cultural Inclusion model proposed by Avery provides us with a way forward because it is the most truly aspirational model of social inclusion. And I want to suggest that Avery's model of Cultural Inclusion has applicability not just for people with a

disability living in remote Australia, but for all people with disability living throughout Australia.

Today is a day about Big Thinking about Social Inclusion and I want to suggest that it is time that we moved beyond cultural safety, cultural security and cultural congruence, incredibly important concepts that they are, and instead let's talk about a cultural led approach to social inclusion.

The author, Richard Flannigan, was a special guest at Garma this year and he had something to say about kinship and Commonwealth,

In Yolngu the word for selfish is *gurrutumiriw*, which translates as lacking in kin, or acting as if one has no kin...

Black and white, we have become kin. We cannot be selfish.

And because we are kin it is not possible for white Australia to pretend that it is not damaged by the war that so damages black Australia, that it is not crippled by the same wounds, that it too is not rendered oddly mute by the same silence.

We can belong here if we choose to anchor our identity in Indigenous Australia's history, a history that must include the cost of the invasion – and the path to that new identity is saying yes to the Uluru statement.

Indigenous Australia is offering the possibility of completing our commonwealth of Australia, a commonwealth brutally deformed at its birth by its exclusion of its First Nations.

Commonwealth is an old middle English word that derives from an older word, *commonweal*, which was understood as a general good that was shared, a common well-being. It suggests a mutuality and shared strength. It evokes relationships, the idea of a common inheritance. It is, you could argue, the counterpoint to the Yolngu word for selfishness, for lack of kinship. Commonwealth *is* kinship.

It is to a completed commonwealth that I wish to belong. A commonwealth not just of states but more fundamentally a commonwealth of kin, a commonwealth of the Dreaming, of 60,000 years of civilisation. That's the land I want to walk to, and it's time we began the journey along the path Indigenous Australia has with grace shown us. To tomorrow. To hope.

As I listened to the many different speakers at Garma this year, it slowly dawned on me what the relationship between the NDIS and Aboriginal people with disability has to do with issues of sovereignty and culture.

We will all be the lesser if we lack kinship, if we are unable to fulfil our reciprocal responsibilities. We have to get it right!

Galarrwuy Yuninpingu extends an extraordinary invitation to us whitefellas to join his people in culture:

What a gift this is that we give you, if you choose to accept us in a meaningful way.

I cannot but endorse this beautiful call to inclusion.

It is such a hopeful call for all of us, as a nation, to belong!

Getting the NDIS right for all people is so important at this time.

Not just people with a disability but for all us.

We will continue to be the lesser if we cannot accept this gift that is being offered.

It is imperative that we accept the invitation.

It is an opportunity that will be just too costly, if lost!

Thank you.

Terry Cleary

References

Andrea Mason Kenneth Jenkins Oration at the NDS CEO Meeting, Sydney NSW; 5 December, 2017 <https://www.pmc.gov.au/news-centre/indigenous-affairs/kenneth-jenkins-oration-delivered-andrea-mason>

Evaluation of the NDIS. Final Report, February 2018, National Institute of Labour Studies, Flinders University.

Warr, D, Dickinson, H, Olney, S, et. al. (2017) Choice, Control and the NDIS, Melbourne: University of Melbourne.

Carney, Dickinson, Malbon and Reeder. "The Vexed Question of Market Stewardship in the Public sector: Examining Equity and the Social Contract through the Australian National Disability Scheme". *Social Policy and Administration* Vo 52, No 1, January 2018 387-407.

Lorna Hallahan. Speech Notes HAD, Adelaide 22 August 2018, Autonomy and self determination: a valued or vulnerable vision for the NDIS.

Galarrwuy Yuninpingu. "Rom Watangu. An Indigenous Leader reflects on a lifetime following the law of the land." *The Monthly* July 2016. <https://www.themonthly.com.au/issue/2016/july/1467295200/galarrwuy-yunupingu/rom-watangu>

Fred Chaney, The Cranlana Oration. June 2018 <https://cranlana.org.au/fred-chaney-cranlana-2/>

Scott Avery (2018) *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. First Peoples Disability Network (Australia), Sydney. Australia.

"Assisting Indigenous Australians in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands to Benefit from the National Disability Scheme (NDIS)". (2014) NPY Women's Council.

"Walykumunu Nyinaratjaku: To live a good life" (2018) NPY Women's Council.