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# update

Issue 84 • Winter 2018 • People with disability: Aboriginal & Torres Strait Islander perspectives

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## People with disability: Aboriginal & Torres Strait Islander perspectives

## By Susan Helyar, Director, ACT Council of Social Service Inc. (ACTCOSS)

This edition of the journal shares insights from Aboriginal and Torres Strait Islander peoples about their experience of disability, their engagement in advocacy to improve the experiences and opportunities of people living with disabilities, and their reflections on service provision. It is a privilege to provide a platform for these insights and to amplify them to our members and other readers.

This edition of the journal also provides information on the services and supports available in the community that are keen to be more accessible, relevant and effective in their work with Aboriginal and Torres Strait Islander people living with disabilities, their families and carers. During NAIDOC Week, there should be lots of opportunities for these services to attend Aboriginal and Torres Strait Islander community led events, during which non-Indigenous people can listen, learn and connect with Aboriginal and Torres Strait Islander peoples.

What a joy it is to share a short excerpt from a book being written by a young Aboriginal man who lives with autism. Thank you for diversifying our content and hopefully encouraging other ACTCOSS journal contributors to use creative expression to share their perspective of the world with others.

#### Join Friends of First Peoples Disability Movement

Any individual or organisation is welcome to join the Friends of the First Peoples Disability Movement. You will receive updates about their work and hear about opportunities to get involved and speak up. Find out more and sign up here: https://bit.ly/2ykpWRr



## Speaking with Damian Griffis, CEO of First Peoples Disability Network Australia

On 4 June 2018, we spoke to Damian Griffis, the Chief Executive Officer of the First Peoples Disability Network Australia (FPDN). Damian Griffis is a Worimi man and a leading advocate for the human rights of Aboriginal and Torres Strait Islander people with disability. Damian has been a central figure in the establishment of both the Aboriginal Disability Network NSW and FPDN. Damian represents FPDN at regional, national and international forums. In 2014, he won the Tony Fitzgerald (Community Individual) Memorial Award at the Australian Human Rights Awards.

Damian spoke with ACTCOSS Policy Manager Craig Wallace about self-identification and the construction of disability in communities, the rollout of the National Disability Insurance Scheme (NDIS), health outcomes for Aboriginal and Torres Strait Islander peoples, the National Disability Strategy and rights to justice.

#### What is FPDN?

We are First Peoples Disability Network Australia (FPDN), a national organisation of and for Australia's First Peoples with disability, their families and communities. Our organisation is governed by First Peoples with lived experience of disability.

We were born of the efforts of advocates who were working from the early 1980s to bring attention to the specific needs of First Peoples with disability and their families. FPDN was established informally in 2010 and registered as a public company limited by guarantee in 2014. Our founders are the leaders of the Aboriginal disability movement and have been working to uphold the rights of our people since the 1980s. Uncle Lester Bostock founded our organisation and remains on our Board.

Find out more about First Peoples Disability Network Australia: **fpdn.org.au/our-community**  How is disability thought about in Aboriginal and Torres Strait Islander communities? What are some of the differences across Australia? Is disability as we construct it actually a notion at all in community?

That's a great question. The first thing to note is that in traditional language there is not a comparable word for disability, so that's a wonderful thing in many ways in the sense that people weren't labelled. There have been some cultural anthropologists who have been able to research different traditional languages, and the common theme across the country is there wasn't a comparable word for disability – so that would suggest that it's an accepted part of the human experience.

More recently there is a discovery at Lake Mungo – which is one of the oldest archaeological sites in the country – of a single footprint and what appears to be a stick, so it would suggest that there was a person with one leg who was participating in community life. I believe that footprint has been dated now to at least 25,000 years. That would suggest that people with disability had a role within community and were valued.

Another example that is a more contemporary one - and it's an amazing film - is the Gurrumul film. It's a story of disability in a lot of ways, yet it isn't, if you get my drift. There's no doubt that when his family is interviewed there is a sadness that he was blind, but they also see him as a messenger and someone that is a leader – it's not like he lives his life as a blind person; he's a valued member and leader of the community. Even so, there is a part during the film where he is supposed to go on an American tour - he's about to make it in America and they've got six months' worth of gigs lined up and he basically doesn't show up because he's got a commitment to participate back in his community in ceremony and stuff, so again, it's about leadership. There has been some evidence that people with disabilities have been accepted in community as traditional healers that disability is part of the human experience.

That is to romanticise it slightly, however. There are some parts of the country where some communities talk about disability as a consequence of bad karma, so it's a bit of a mix. There is a theory that we're working on here at FPDN that this coincides with the arrival of missionaries – that it was actually corrupted by the old church view of disability, which is problematic in some places.

A lot of families are very reluctant to come forward and seek help for their family member with disability. They worry about their child being taken away and all those sorts of things which are very real concerns still around the country. Having said that, in some communities around the country, having a disability may not be viewed as anything particularly different because everyone struggles in some of our really poor communities.

No one's got a job and everyone is just trying to survive, so in some ways what we find interesting in the National Disability Insurance Scheme is that in western culture it's all about defining people and finding ways to not include people. The recent debate around autism, for example, where they are trying to reduce the number of people in the scheme... but in Aboriginal culture you are not looking for reasons not to support people. You are looking for a reason to help one another out, so that's an interesting and problematic thing.

## Did that cluster of issues lead you to then pull together the ten point plan?

Yeah, definitely. We were really concerned at the outset of the NDIS that we needed to be front and centre at the very start. And we also knew that government doesn't do this stuff well and often overlooks the needs of Aboriginal and Torres Strait Island people and comes at them as an afterthought or doesn't prioritise needs. But as you've heard me say, it's difficult to think of any more disadvantaged people than Aboriginal and Torres Strait Islander people with disability. So we thought we should be very prescriptive and we developed a ten point plan. We would see things progressing in a piecemeal way - we're picking at the edges at the moment. We're very frustrated because we have had a plan since 2013 since the NDIS was called Disability Care, and it's now a matter of, 'come on, let's get on with the work,' really. So the ten point plan is still very much alive.

## Some people have described the NDIS to me as a failure of Commonwealth administration as

#### much as anything. If anyone knows what that looks like – thinking back to the Commonwealth intervention (in the Northern Territory) – it's Aboriginal and Torres Strait Islander people...

Yes, I think what we have to remember is the Commonwealth doesn't do service provision, except in areas of army, customs and Centrelink – pushing money out the door. And the risk you've got is that this has a Centrelink feel to it now. I think that's the problem – that the Commonwealth is not experienced in service delivery apart from those areas and pushing money out – it's actually a conduit to services, but the lack of the Commonwealth's experience is starting to show.

#### Thinking about the broader National Disability Strategy – what should they focus on? Putting the specialist stuff aside...

Well – that's a great question. I sometimes think the things we don't do well in this country is really big picture stuff. So I wonder if it sometimes comes back to attitudes. I think the strategy has got to be about ensuring that Australians with disability have their rightful place in their own community and the wider community, and that's got to be the driver behind it. I think you've got to have the narrative – the big picture – otherwise you just have this whole series of tasks – some you get right and some you don't, when in the end it's about saying, isn't this about ensuring people with disability are more than just a visible presence in their community, they are leaders in their community? I worry that strategies like this need to have a heart to them.

#### When I was a national leader I used to ask – what's our project for disability? That I didn't understand what it actually was. What's Australia actually working towards here...

That's a great call because I think the other problem is that you then see that play out at a micro level, even though the NDIS is not a micro program, but one of the things we need to call out is that the NDIS won't change infrastructure, for example. It won't build footpaths in Wadeye – you might get individual packages, but you can't use them because you still can't move around your community. So again, it's that kind of individualised approach versus a bigger picture approach. I think that's one of the problems we still have here – and in Aboriginal Affairs – we don't talk about and we don't have the uncomfortable conversations well in this country. Don't you think? Yes, we carve them up – often by allocating small achievable bits to jurisdictions – but what we aren't good at is slow, arduous, negotiated change across, say, a ten year timeframe that's outside the political cycle...

Yep, that's bang on. Where are the visions? Where are the ten year, fifteen and twenty year visions and what's wrong with that?

We're stuck in small cycles, which is all about the political cycle, but surely leadership is about looking well beyond what is in front of you.

So why aren't we having discussions around making the country universally accessible within 20 years?

I just give that as an example. But instead, we pick little stuff and we say, 'Oh well, we might make a certain number of training stations accessible'.

#### If I was to look through that frame and pick one area where we seem to be stuffed at the moment, it's health. And this combination of a lack of prevention, people being shunted into bulk billing and not getting close attention, and diagnostic overshadowing. Do you agree or is it something else? And what does that look like for Aboriginal and Torres Strait Islander people?

I think diagnostic overshadowing is a major problem in our community – it's a problem across the disability community. Scott Avery has been doing some research on that very issue and we encounter this all the time.

This plays out very adversely in an Aboriginal context. To not put too finer point on it, this results in deaths. Take Miss Dhu's situation in Western Australia, where she was viewed as an Aboriginal woman who was being a trouble maker, but it turns out she had a really significant disability and that was overlooked and she died, despite being taken to hospital three times in 24 hours. She was viewed as being a difficult person, but she actually had a legitimate issue – she had a broken rib. And she died of toxic poisoning. We see this play out all the time.

There was an example in the Sydney newspapers last week of another death in custody in Long Bay, where an Aboriginal man in his 20s with significant mental health issues died in custody. And he wouldn't have been getting any significant support around his mental health. He was just a prisoner.

Diagnostic overshadowing is a massive issue. The one we all hear too often is around a person with cerebral palsy being accused of being drunk. I'm always reminded of a personal experience when I was doing support work with a man with an intellectual disability. Fortunately, we had a good working relationship and one day he said, 'Look at this,' and he had a hernia that was enormous and I had to rush him to hospital; and sure enough, he had immediate surgery for a strangulated hernia. But the issue was he'd been going to doctors all year and what had happened is that people only ever contemplated him as person with an intellectual disability; they didn't think he might have a physical issue playing out. That stuff happens all the time.

I think the NDIS is a bit problematic there, too, because I hear people having to pick their disability – you go, 'I've got physical disability but heaven forbid if I start talking about my mental health needs.'

#### Do we still have Aboriginal and Torres Strait Islander people with disability in remand?

Yes, a big problem, particularly in Queensland. The prevalence of disability in the Aboriginal prison population and in the main prison populations is alarming.

I did a radio interview in the Kimberly and there was a guy who was the CEO of the Aboriginal Legal Service in WA, and he said that 90% of his clients – in his view – had a disability. Even if that's not precise, what he's actually saying is that this is a major issue.

I think this is one of the hidden social issues in Australia. I think prisons are clearly becoming more and more like the old mental health institutions and I think they are becoming the default. The one we come across a lot are Aboriginal young people who you would say might have a borderline intellectual disability. So they might have gone to school since about 14 and they might have been unnoticed and had a borderline impairment that nobody ever bothered to support them with or picked up. And then they end up being suspended or expelled or they just stop going to school.

And then they start hanging around the shops and get moved on by police and then they are moved on to juvenile justice – that story's very common.

FPDN website: fpdn.org.au



First Peoples Disability Network Australia

#### The ten point plan

FPDN developed a ten point plan for the implementation of the NDIS in Aboriginal and Torres Strait Islander people with disabilities. The development of this ten point plan is based upon extensive consultation, as well as drawing upon the decade long experience of the FPDN in advocating for the rights of Aboriginal and Torres Strait Islander people with disabilities.

The plan was launched in May 2013 at Parliament House, Canberra.

Ten point plan:

- Recognise that the starting point is the vast majority of Aboriginal people with disability do not self-identify as people with disability. This occurs for a range of reasons including the fact that in traditional languages there are no comparable words for disability. Also, many Aboriginal people with disability are reluctant to take on the label of disability; particularly when they already experience discrimination based on their Aboriginality. In many ways disability is a new conversation in many communities. In these instances the NDIS is starting from a baseline position. As a consequence change in this area is likely to happen on a different timeline to that of the mainstream NDIS.
- Awareness raising via a concerted outreach approach informing Aboriginal and Torres Strait Islander people with disability, their families and communities about their rights and entitlements, and informing Aboriginal and Torres Strait communities about the NDIS itself and how to work this new system effectively. There is no better way to raise awareness than by direct face-to-face consultation. Brochures and pamphlets will not be appropriate as this is a new conversation in many communities.
- Establish the NDIS Expert Working Group on Aboriginal and Torres Strait Islander People with disability and the NDIS. In recognition of the fact that there is a stand-alone building block for the NDIS focused upon Aboriginal and Torres Strait Islander people with disability, FPDN views it not only as critical but logical that a specific Expert Working Group be established to focus on Aboriginal and Torres

Strait Islander people with disability. The new working group would operate in the same way the four current working groups do, that is it would be chaired by two members of the National People with Disability and Carers Council. To ensure its effectiveness but also critically to influence prominent Aboriginal leaders as well as the disability sector, members would be drawn from Aboriginal and Torres Strait Islander people in community leadership positions, as well as involving prominent disability leaders. The FPDN believes such an approach is warranted not only because of the degree of unmet need that is well established but also because this has the potential to be a very practical and meaningful partnership between government, the non-government sector, and Aboriginal and Torres Strait Islander communities.

- Build the capacity of the non-Indigenous disability service system to meet the needs of Aboriginal people with disability in a culturally appropriate way. Legislate an additional standard into the Disability Services Act focused upon culturally appropriate service delivery and require disability services to demonstrate their cultural competencies.
- Conduct research on the prevalence of disability and a range other relevant matters.
   Critically, this work must be undertaken in partnership with Aboriginal and Torres Strait Islander people with disability to ensure a culturally appropriate methodology. There remains very little reference material about disability in Aboriginal and Torres Strait Islander communities. This needs to be rectified to ensure that we are getting a true picture of the lived experience of Aboriginal and Torres Strait Islander people with disability.
- Recognise that a workforce already exists in many Aboriginal and Torres Strait Islander communities that does important work, often informally. This work needs to valued and recognised, with the potential for employment opportunities in some communities.
- Recognise that it's not always about services.
   Many communities just need more resources so that they can continue to meet the needs of their own people with disabilities. There may

be perfectly appropriate ways of supporting people already in place, however what is often lacking is access to current technologies or appropriate technical aids or sufficient training for family and community members to provide the optimum level of support.

- Recruitment of more Aboriginal and Torres Strait Islander people into the disability service sector.
- Build the capacity of the social movement of Aboriginal and Torres Strait Islanders with disability by supporting existing networks and building new ones in addition to fostering Aboriginal and Torres Strait Islander leaders with disability. These networks play

a critical role in breaking down stigma that may exist in some communities but are also the conduits for change, and will be integral to the successful implementation of the NDIS in Aboriginal and Torres Strait Islander communities.

 Aboriginal and Torres Strait Islander 'Launch' sites focused upon remote, very remote, regional and urban settings. It is critical that this major reform be done right. Therefore it is appropriate to effectively trial its implementation. To this end, FPDN can readily identify key communities that would be appropriate as trial sites.

# Aboriginal & Torres Strait Islander people & intellectual disability

Extract from How to Hear Me: A Resource kit for Counsellors and Other Professionals working with people with Intellectual Disabilities by WWILD Sexual Violence Prevention Association Inc. Published on the QCOSS Community Door website: communitydoor.org.au

A ccording to the Australian Bureau of Statistics, in 2008, 50 percent of Aboriginal and Torres Strait Islander people aged over 15 had a disability or long-term health condition.<sup>1</sup> Aboriginal and Torres Strait Islander adults were 1.5 times more likely than non-Indigenous Australian adults to have a disability or long-term health condition, and were more than 3 times more likely to have an intellectual disability. In 2008, 7.7 percent of Aboriginal and Torres Strait Islander people in Australia (more than 25,000) had an intellectual disability. A similar number had a psychological disability.

Aboriginal and Torres Strait Islander people with disabilities often have unique needs, yet they continue to be 'at the periphery of all aspects of the disability sector.<sup>2</sup> The lack of culturally-appropriate disability services and the different understandings of the concept of 'disability' in many Aboriginal and Torres Strait Islander communities make acknowledgement of the rights and needs of people with disabilities difficult to achieve. Griffis identifies these other considerations:

- Identifying as a person with a disability (that is, as a person who will receive disability support or services) is seen to add to the already significant experiences of discrimination that arise from having the label of 'Aboriginal person'. There is understandable reluctance to take on additional negative labels
- There are often no comparable words for 'disability' in traditional languages, which suggests that the experience of 'disability' may have been accepted as part of the normal range of human experience
- Aboriginal people and their families can sometimes experience significant stigma due to a cultural belief that disability is the result of 'married wrong way' or other wrong doings on behalf of the family or parents. This is more likely in communities where a more traditional lifestyle is practised
- The predominant medical model of disability (and the Australian Government's Close the Gap initiative) has focussed heavily on primary health

interventions – in contrast to the social model of disability, which acknowledges and attempts to deal with the social construction of disability and the injustices that contribute heavily to people's negative lived experience of disability

 Most Aboriginal and Torres Strait Islander people prefer to seek assistance from Indigenous organisations; few of these provide disability-specific services.<sup>3</sup>

Cultural awareness is an extremely important aspect of counselling practice with Aboriginal and Torres Strait Islander people, and the differences in cultural and life experiences between Aboriginal and Torres Strait Islander people and non-Indigenous Australians can be a big deterrent for Indigenous Australians in seeking assistance from mainstream service providers.<sup>4</sup>

The history of mistrust of white Australians since colonisation has a significant impact on Indigenous people's ability to trust non-Indigenous counsellors in a clinical setting. Where possible, it is important to engage with Indigenous services, community members or family members who can support an individual's engagement with a counsellor.

Relationships and kinship ties are central to the social and cultural values of many Aboriginal and Torres Strait Islander people, and it is imperative to make connections with and show respect for the family members and wider community that the person belongs to. Developing good networks within the community and with Indigenous service providers will both increase practitioners' cultural understanding as well as their clients' levels of trust in individual practitioners as people who care about their lives and want to understand their needs and lived experiences.

Counsellors need to be mindful that not all kinship ties will be helpful or supportive to their clients, and that a lot of people may be unwilling to discuss potentially 'shameful' personal issues with a worker if they think that family members will find out. These issues need to be explored and assurances need to be made to the client that family and community are welcome to be involved as much or as little as the client chooses. It might be helpful to ask a trusted person in the client's life to support them in the initial stages of counselling – to define the meaning of confidentiality for that particular person, whom they want involved, whom they do not want involved, and teasing out the issues of confidentiality and duty of care.

'Talk-based' therapies can be difficult for some Aboriginal and Torres Strait Islander people, often because practical issues relating to daily living and resources take precedence over more personal, psychological issues.<sup>5</sup> The disadvantaged socio-economic and physical living conditions that many Aboriginal and Torres Strait Islander people live with are likely to be intensified for people with intellectual disability.

Find more resources for your community organisation at QCOSS' Community Door:

communitydoor.org.au

See page 19 for footnotes.



People With Disabilities ACT (PWD ACT) is a disabled people's organisation run by people with disabilities for people with disabilities. PWD ACT provides its members with information and peer support and works to inform the community about issues affecting us. We advocate from a human rights framework for the removal of barriers to our participation and inclusion in the community and work to inform the discussion of issues affecting people with

disabilities and to promote access especially in the areas of housing, transport, education, employment and the physical environment.

PWD ACT has regular member morning tea functions and an active social media presence.

Membership is free to people with disabilities. For more information contact us on 6286 4223 or visit our website www.pwdact.org.au

## Angela's story – the providers let me down

#### **By Angela**

Last year ACTCOSS published our Stories of Transition – a collection of real stories as told by Canberra people with disability and families experiencing the transition to the National Disability Insurance Scheme (NDIS). One of the most important stories was from Angela, who spoke to the failure of providers to meet her family's needs as well as poor responses from health and education.

Nearly a year on, this story remains as truthful as ever. Angela, who is a mother of Aboriginal descent, has agreed to us republishing it for this edition of the journal.

#### Angela's story

Sometimes you need the kinds of change and supports that can't be provided in a marketplace but demand responses from other systems, like education and mental health...

If the head of NDIS was sitting in this room I'd say – come and live my life. Your NDIS does not cover anything. It doesn't help me, my children, my family whatsoever.
– Angela

As a mother of two children with a disability, I need a range of services: occupational therapy, mentoring, cognitive behaviour therapy, psychologist, counselling and anger management.

My daughter is 8 and my son is 11. My daughter got diagnosed with autism and anxiety in December last year. She's a perfectionist at school but at home her behaviours are quite on display. At the moment I pay for all my daughter's horse therapy. Whereas my son's behaviours are school-based but his mental health has deteriorated in the last 12 months. He is now voicing suicidal ideation.

We just had our NDIS review in January for my son. We've been going 15 months. I originally brought in a service to provide in-school support and also have a one-on-one worker to provide him socialisation, counselling and behavioural strategies. We had a big meeting. I took time off work. The meeting took two hours. The service provider charged nearly \$400 for the two hour meeting but never delivered any services. So I've had no services. The only services I've managed to get is because I self-manage and these are new bedding, mattress protector and doona. That's the only services I've got through NDIS.

I would like counselling, in-school support and services to help my son have a friend. He really needs a friend. In fact, on his 9th birthday because he had behaviour at the school swimming carnival with approximately 200 parents witnessing it, they subsequently boycotted his birthday party. We haven't had a birthday party since.

My son is brilliant at Lego designs and technics. He's absolutely like an expert. I'd love to have something that focuses in on those and harnesses that career path.

I was very fortunate with NDIS and the planning process because I worked in the ACT community sector and had a better understanding of NDIS. I actually had people I knew and was really fortunate to get planners I requested.

Unfortunately it was the service providers who let me down.

If I could I would request to have my son removed off NDIS, because there's no difference for us. But no one in NDIA has been able to articulate how you remove someone from NDIS unless they die.

The only reason I continued to do my son's review in January was because I might need the transport aspect next year when he's in high school and because NDIS took that from education. So that's the only reason I have continued to play the game.

Our daughter is not on NDIS after our experience with it. I have a private provider.

We tried to get a mainstream provider, they said bring her out. She loved it. And then they turned around and said sorry we've got an 18 month waiting list. Then I said then why did you tell us to bring her out here and set her up? So I sourced a private provider and we're really lucky he's actually a social worker by trade who specialises in disabilities in children. So it's working brilliantly for her.

I think personally the low point for me was the moment in January when my son's mental health deteriorated and there was a critical incident at school and I was just told to just sit in the emergency with him waiting for Child and Adolescent Mental Health Services (CAMHS).

I've only had clients been taken by CAMHS when they have actually done something. They only go at crisis.

I'm worried about where we go from here because my son has not transitioned back to Term 2 well and the school called an urgent meeting on Monday. My husband rang me from the meeting and it was disclosed in the meeting that my son's been left in a classroom by himself for most of Term 1.

I don't know if he'll be at school after this meeting on Thursday and I have nowhere to put him. He hates school. He has no friends. He actually articulated to me school sucks any joy out of his life. He just wants to be left alone to do his own thing. NDIS can't support me in that.

Ideally I'd like my son probably to be home schooled for a proportion with someone but also have the social engagement. Also work on what his employable skills will be because I'm focused on him growing up and being able to be independent. And that's where I see he's brilliant at computing. He's brilliant at engineering. But his education needs to be tailored to his strengths, not his weaknesses.

He would be better off being home schooled given the level of trauma he's experienced. Also I'm very aware that if I do that how's he going to get his social skills? So, I think it's also putting him into groups with activities with people that have the same interest, and then having the behavioural support with counselling to help him manage his anger and his anxieties.

I'm really looking at where he's going to be at 18. But I'm now sitting here as a mother since November last year thinking I'm going to lose him.

If the head of NDIS was sitting in this room I'd say – come and live my life. Your NDIS does not cover anything. It doesn't help me, my children, my family whatsoever.

Read more in the ACTCOSS publication *Stories of Transition*: actcoss.org.au/publications/advocacypublications/stories-transition



Join your voice with ours: Speak up on issues important to women with disabilities in the ACT.

Free Membership at wwdact.org.au For women with disabilities & supporters

## **Carers ACT celebrate launch of Reconciliation Action Plan**

#### **By Carers ACT**

Carers ACT recently launched its first Reconciliation Action Plan (RAP) during National Reconciliation Week, which actively recognises and supports the unique needs of Aboriginal and Torres Strait Islander carers and their families.

'Our RAP lays a platform for us to engage our staff, stakeholders and community in working towards meaningful reconciliation,' said Carers ACT CEO Lisa Kelly. 'It reflects our commitment to be part of a community which celebrates diversity, upholds equality and recognises and respects Aboriginal and Torres Strait Islander peoples as the First Australians,' she said.

'We are working towards this vision by ensuring that Aboriginal and Torres Strait Islander carers have a voice in informing how carer services can best be shaped and delivered, to provide the support they need,' said Lisa Kelly. 'This reflects the organisation's long and proud history of advocating for and raising the awareness and profile of carers.'

'We are also working to reduce barriers to ensure Aboriginal and Torres Strait Islander peoples have access to services, information and supports that are culturally appropriate and that meet their needs,' she said.



Nguluway Art Group members.



Lisa Kelly and Jennifer Merriman at RAP launch.

Carers ACT have a dedicated program and coordinator to support Aboriginal and Torres Strait Islander carers and their families which provides respite and cultural opportunities. The fortnightly Nguluway Cultural Art Group, for instance, allows carers to gather together, share food and stories, build relationships, connect to culture and have an important therapeutic break from their caring role.

'They also create the most beautiful artworks,' Ms Kelly said. 'Their latest collaborative project, presented to Carers ACT at the launch of our RAP, was a special eight-piece mural depicting the serpent and its journey. Each artist's piece reflected their own cultural journey and we will be hanging the mural in our main hallway as a beautiful reminder to us all of our own journey towards reconciliation.'

Enquiries: Carers ACT 1800 052 222, email carers@carersact.org.au or visit their website at www.carersact.org.au. Copies of the RAP are available on the website.



www.anglicare.com.au

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## Free autism support for families in Canberra

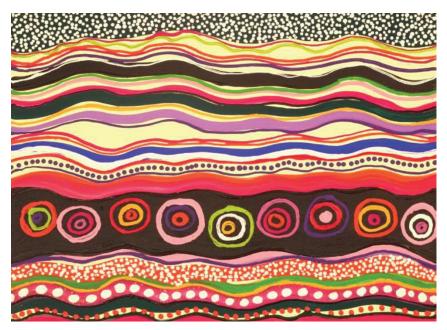
#### **By Positive Partnerships**

Positive Partnerships proudly works with the Canberra community by holding Get Together workshops, designed to support families, schools and service providers who care for or support Aboriginal and/or Torres Strait Islander children on the autism spectrum, and students with other diverse learning needs.

A large amount of community consultation occurs to make sure the Positive Partnerships workshops are successful. Back in October 2017, the Positive Partnerships team met at Winnunga Nimmityjah Aboriginal Health and Community Services with a group of key drivers in the Canberra community who support Aboriginal and/or Torres Strait Islander children on the autism spectrum, to consult on a series of workshops coming up in the community. The content of the Positive Partnerships workshops were discussed and how the approach would best meet the needs of the families.

The community consultation is also an opportunity to work with a local community member in the role as Aboriginal Community Contact. Ebony Joseph from the Child Development Service proceeded to engage families to attend the workshop by providing transport, childcare, information and support.

On Wednesday 22 November 2017, Positive Partnerships held two successful workshop sessions at the ACT Aboriginal and Torres Strait Islander Cultural Centre. These workshops were a chance for parents, carers, grandparents and service providers to share



A Spectrum of Colours, 2018, by Maria Watson-Trudgett (Language Group: Wiradjuri).

My vision for this artwork was to highlight the diversity of autism by using many colours and movement in my painting. All colours, dots and wavy lines represent the diverse spectrum of autism. Black band represents Aboriginal communities. Coloured circles represents Aboriginal family units and their individual family journeys with a child on the spectrum.

and discuss ways to help support young people on the autism spectrum in a safe and culturally supportive environment.

A beautiful sunny day nestled amongst the trees and surrounds, everyone gathered together for some robust discussions about their children. We listened to the many and varied journeys of autism and the different ways children learn, behave and cope with their environments by exploring a tool called 'The Individual Child's Storyboard'.

In the afternoon, service providers and school staff from the community who support Aboriginal families and children on the autism spectrum attended a session where many of the Positive Partnerships tools and strategies were shared. They left inspired and keen to try these practical approaches to building on the relationships with the families they support.

Ebony Joseph continued to work closely with the Positive Partnerships team over the next two months, keeping families engaged and looking at how we could support more people to attend our the next workshop.

During February 2018, Positive Partnerships returned to the ACT Aboriginal and Torres Strat Islander Cultural Centre for their second Get Together for community.

Both sessions provided a day for parents, carers, grandparents to share and discuss ways to help support children on the autism

spectrum and those with other disabilities. Participants were introduced to a new resource, 'The Child's Storybook', and by listening to many and varied stories from families across the country, participants were then able to use this resource to celebrate the strengths and skills of their children while exploring the best ways of understanding their behaviours and way they learn. The session ended by focusing on working together, ensuing everyone left with a planned approach to next steps.

Positive Partnerships would like to thank the Aboriginal community of Canberra who have been incredibly supportive in the planning, promotion and delivery of these fully funded and valuable workshops. Thank you to Winnunga Nimmityjah Aboriginal Health and Community Services, Gugan Gulwan Youth Aboriginal Corporation and the Child Development Service for your support.

Families, schools and services can continue to engage with Positive

Partnerships resources and supports through our website: **positivepartnerships.com.au** 

The Positive Partnerships initiative is funded by the Australian Government Department of Education and Training through the Helping Children with Autism Package and is delivered by Autism Spectrum Australia.



## Woden Community Service working together, enriching lives

### Are you looking for NDIS Support Coordination or Direct Support Services?

Woden Community Service can help you take control of your NDIS plan by working with you to:

- Navigate the NDIS and resolve problems or issues that have arisen with NDIS funded supports.
- Ensure you receive optimum benefit from your NDIS funding by helping you find the right service providers and ensuring existing service providers maintain a high-quality service.
- Expand your existing supports, increase your participation in the community and build your existing relationships.

We have two teams providing NDIS direct support services - one providing direct services to people living with a range of disabilities including physical, intellectual and neurological disabilities that focuses on capacity building and the other with expertise in mental health and psychosocial recovery.

Our team will work with you one-on-one and in a group setting towards your NDIS goals. This may include working with you to increase your participation in the community, building your existing relationships, maintaining your health and wellbeing or engaging in paid employment or volunteer opportunities.

We support people of all ages and abilities. Our team comes from a multidisciplinary background, and together have an in-depth knowledge of the community sector in the ACT.

Give us a call today on 02 6282 2644 or email ndis@wcs.org.au

## Knights of Nowrania

## Creative writing from a young Aboriginal author

## Introduction by Julie Moore, creative writing & illustration by Liam Ingrey

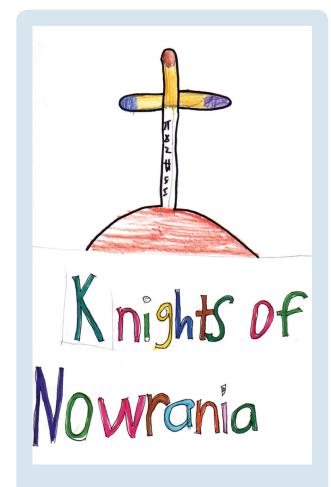
Y name is Julie Moore and I come from Wreck Bay Aboriginal Community in the Jervis Bay Territory. You may have met me at 'Aboriginal Cultural Awareness Training', which I deliver at ACTCOSS.

I would like to proudly introduce my grandson, Liam Ingrey. He has special needs in the area of autism and will soon be turning 17 years of age – gee, almost grown up! From birth, there were signs such as delayed development and no communication. He really didn't like loud noise. But Liam could communicate with his twin sister. They spoke their own language that no one could understand. If we needed to talk to Liam, we would tell his sister and vice-versa. Our family and our community have all taken responsibility to 'grow' Liam. Liam was diagnosed at 3 years of age whilst attending the Wreck Bay Day Care. The day care introduced us to the Noah's Ark Centre in Nowra, which has provided continued support since Liam's diagnosis.

Today Liam can hold a conversation on any subject – usually a subject of his choice such as dinosaurs, animals and his passion for medieval history. Whilst Liam is very knowledgeable in a number of areas, he is especially well read about the dinosaur world and its place in history. He also possesses a major talent for story writing and uses his iPad to feed this passion. The iPad was obtained pre-NDIS as part of his care package; it's never far away from Liam's grasp.

Liam is now attending high school. As part of his English class, the school has encouraged Liam to write a story based on his interests. He is currently writing his first book, which is set in medieval times and is called *Knights of Nowrania*. Liam features as one of the main characters, along with many of his school-based peers in his story. Liam also gains great satisfaction in illustrating his own books.

Liam would like to share an extract of Chapter 1 with ACTCOSS readers.



#### Knights of Nowrania: Extract from Chapter 1

The eldest son, the Rainbow Serpent used the Crystal of All Universes, an artefact that can create portals from TV show to video games and all realities, to absorb the powers of the dark god. Victory was glorious around that time ..... Until later on. In Arthurian England, a young boy called Coenette, the son of legendary knight sir Lancelot had visions of Lord Liam being free, loose upon Nowrania, conquering Australia, then the entire world. King Arthur tasked the 18 year old to Australia in order to stop the cosmic threat. Boarding the boat, it took 32 to 40 long days to get to the country until he was stopped by the Australian National Guard. "Stop in the name of Jarl Liamos Ingreyus, what be your status peasant" he said to the young knight and he said "I came here to stop your king from killing the multiverse" and his swordsman skills are more than a match to the guards and they ran off to their master.

(Illustration: The Sword in the Stone, by Liam Ingrey)

We are looking forward to reading the next chapters of Liam's book. Thank you for reading Liam's story!

## Social & economic wellbeing of Aboriginal & Torres Strait Islander people with disability

#### Extract from the paper by the Australian Bureau of Statistics (ABS)

here are significant differences between the experiences of persons with and without disability across many areas. The lower rates of educational attainment, coupled with poor employment outcomes contribute to lower life satisfaction. These factors along with a lack of adequate support impact on Aboriginal and Torres Strait Islander people with profound/severe disability and curtail their capacity to effectively interact in the community or access appropriate services.

On the other hand, an Aboriginal and Torres Strait Islander person's cultural connections cannot be underestimated and appears to provide a levelling factor in one's lived experiences where very little difference exists between peoples' experiences regardless of their level of disability or activity restriction. These connections to culture, family and the community alongside active participation in cultural activities can help lessen feelings of isolation and provide people with supportive networks.

Understanding the benefits of connection to culture and giving it due consideration can only assist in improving the services provided to Aboriginal and Torres Strait Islander peoples with disability and their access to and trust in such services.

Read the full article Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with Disability at the ABS website: abs.gov.au

## NDIS Aboriginal & Torres Strait Islander engagement strategy

From the National Disability Insurance Scheme website

Drawing upon the existing strengths and features of rural and remote communities, along with engaging in the 'proper way' with Aboriginal and Torres Strait Islander communities are key components of the National Disability Insurance Agency's (NDIA) Aboriginal and Torres Strait Islander Engagement Strategy (pdf).

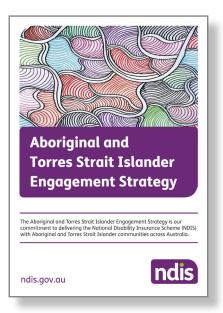
The strategy focuses on enabling quality engagement, service delivery and leadership to ensure the successful delivery of the National Disability Insurance Scheme in Aboriginal and Torres Strait Islander communities across Australia.

The strategy was developed drawing on the knowledge

and experience of the NDIA trial sites and the expertise of the Aboriginal and Torres Strait Islander Reference Group and associated working groups.

Highlights of the Aboriginal and Torres Strait Islander Engagement Strategy include:

- The adoption of an 'l' model phased approach of 'introduction, initiation and invitation' for establishing sustainable relationships with Aboriginal and Torres Strait Islander communities
- Principles for engaging in the 'proper way' with Aboriginal and Torres Strait Islander communities



 10 key engagement priorities for Aboriginal and Torres Strait Islander peoples with a disability.

Read the documents in Easy English – Aboriginal and Torres Strait Islander Engagement Strategy (pdf).

Find out more at the NDIS website: **ndis.gov.au** 

## **Aboriginal & Torres Strait Islander Community Bus**

#### By Ian Corey, Senior Manager, Flexible Transport Office, Transport Canberra

The Transport Canberra Flexible Transport Team delivers the ACT Government's suite of specialised transport services including the network design and operation of the special needs school bus network, the Community Transport Co-ordination Centre (CTCC), the Flexibus Service and the Aboriginal and Torres Strait Islander Community Bus. Services are specifically designed to meet the needs of those in the community who cannot easily access regular bus services, including the elderly, Aboriginal and Torres Strait Islander people and Canberrans with a disability.

In regard to the Aboriginal and Torres Strait Islander Community Bus – in 2012 the ACT Government commissioned a study into Aboriginal and Torres Strait Islander transport disadvantage. The study identified a significant risk of social isolation in the group through a lack of targeted transport. The Aboriginal and Torres Strait Islander Community Bus now provides bookable demand transport for Elders, family groups, social and sporting activities, using a wheelchair accessible minibus. The service has a dedicated driver whose role is to enable improved access to services through accessible transport. The program also provides for the minibuses to be used by groups out of hours to attend cultural events, sporting and recreational and activities that allow for community connection (approval is required at least three working days in advance).

The Transport Canberra Community Transport Coordination Centre provides a single touchpoint where eligible passengers can book travel on both the Flexibus and the Aboriginal and Torres Strait Islander Community Bus from their homes to connect to shopping, medical appointments or social connection. The CTCC can be contacted by calling 02 6205 3555 during business hours or via email at **fbs@act.gov.au**.



#### How does the bus work?

The Community Bus operates Monday to Friday during business hours. If you need transport in and around Canberra, you can make a booking for the bus to pick you up and drop you off.

The mini bus has 12 seats and wheelchair access and can be booked for groups and events.

The bus can go as far as Queanbeyan, Yass, Cooma, Goulburn and Braidwood.

#### How do I book the bus?

To book a trip on the bus simply email your details to **communitybus@act.gov.au** or call **(02) 6205 1116** or **13 17 10**. You need to make your booking two days before you want to travel so we can schedule you in. *When making your booking we need the following details:* 

- address of pick up location
- pick up time
- address of drop off location
- how many passengers are catching the bus.

The bus will try to take the quickest route to your destination, however it may have to stop for other passengers in different locations. You will receive a confirmation email when your booking is approved.

#### Who can use the bus?

The Community bus is available to all Aboriginal and Torres Strait Islanders living in and around Canberra who do not have easy access to an ACTION bus.

We welcome all passengers especially:

- Elders in the community
- Parents with young children who have limited transport alternatives
- Social groups
- Sporting teams (by arrangement)
- People who are isolated and cannot access normal travel options

For further information contact the Flexible Transport Office on (02) 6205 1116 or 13 17 10.

ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITY BUS

## **Unfinished business: Art exhibition**

A photographic exhibition that tells 30 stories of Aboriginal and Torres Strait Islander people living with disability.

The artist Belinda Mason and documentary filmmaker Dieter Knierim have worked in close collaboration with the exhibition's story tellers to reveal their experiences via 3D lenticular photographs, voice, video and text. The exhibition was launched in September 2013 at the Palais des Nations in Geneva, Switzerland with the support of the First Peoples Disability Network and the Australian Government. It has since completed a significant tour across Australia and was showcased at the 2014 United Nations World Conference on Indigenous Peoples in New York. The Canberra showing of the exhibition, firstly at Tuggeranong Arts Centre and now at Canberra Museum and Gallery (CMAG) is supported by The Australian Government, Department of the Prime Minister and Cabinet.

The exhibition runs until 23 September 2018.

CMAG website: cmag.com.au

## Disability Employment Provider Expo – 3 Aug

The ACT Public Service Employment Inclusion Team in coordination and support from the Education Directorate will hold the 2018 Disability Employment Provider Expo on the 3 August 2018.

This is an opportunity to connect job seekers, with a disability, with specialist Employment Providers, who are able to provide support and assistance in looking for and commencing employment.

Attending the Expo will be a range of representatives from the specialist Inclusion Employment Providers from across the ACT/Queanbeyan, including Max Employment and Connexions VTEC – who provide employment services and training support to Aboriginal and Torres Strait Islander People.

Additionally, representatives from various work areas and employers will be present to provide advice about future employment possibilities.

This is a free event and everyone is welcome.

So, if you're looking for work, you will be soon or have recently

left school, or you just want to learn more about the Inclusion Employment Providers, come along to find about these services and possible future employment options.

The Disability Employment Provider Expo will be on Friday 3 August 2018 at the Hedley Beare Centre for Teaching and Learning, 51 Fremantle Drive Stirling ACT, from 9am-2pm.

For more information contact the Inclusion team on email: inclusionemployment@act. gov.au phone 02 6207 2520 or 02 6205 3629.

## **NAIDOC Week: 8-15 July 2018**

N AIDOC Week celebrations are held across Australia each July to celebrate the history, culture and achievements of Aboriginal and Torres Strait Islander peoples. NAIDOC is celebrated by Australians from all walks of life. The week is a great opportunity to participate in a range of activities and to support your local Aboriginal and Torres Strait Islander communities.

This year's NAIDOC Week theme, 'Because of her, we can!', will celebrate the invaluable contributions that Aboriginal and Torres Strait Islander women have made – and continue to make – to our communities, our families, our rich history and to our nation.

To learn more about NAIDOC, go to the National NAIDOC Committee website: naidoc.org.au



## Links to information & resources

## Fetal alcohol spectrum disorder (FASD)

Let's Make FASD History – Communique from APO NT FASD Forum 2018 – Article from APO NT: amsant.org.au/apont

Fetal alcohol spectrum disorder (FASD) is an impairment to the brain caused by fetal exposure to alcohol during pregnancy. A landmark Top End FASD forum was held in Darwin on 30-31 May 2018, bringing together Aboriginal leaders, FASD experts, Aboriginal community controlled organisations, government representatives, medical professionals, and non-government organisations. This communique outlines key messages to be taken into account in addressing FASD in Aboriginal communities.

Nine out of ten young people in detention have mental disability, study finds – Article from SBS: sbs.com.au

A study has revealed that nine out of ten young people in detention have a form of mental impairment from brain damage or injury, while three out of ten have alcohol related brain damage.

## Aboriginal prisoners with disabilities

Behind Bars series: Australia's shocking cruelty to Aboriginal people with disabilities – Articles from New Matilda: newmatilda.com

The abuse of Aboriginal prisoners with disabilities in Australian jails is confronting, and ongoing. In this five part series, Michael Brull profiles the shocking revelations uncovered in a report by Human Rights Watch.

#### NDIS

Disabled Aboriginal people still left behind – Article on NITV: sbs.com.au/nitv

Australians are increasingly embracing the National Disability Insurance Scheme, yet Aboriginal and Torres Strait Islander people with disability continue to be under-represented.

#### Sign language

Our Stories: Season 2, Episode 17 – The Journey Of Gutinarra – Video from SBS On Demand: sbs.com.au/ondemand

Deaf since birth, Gutinarra's first language is Yolnu Sign Language, a language commonly known and widely used among the Yolnu community.

### **ACTCOSS staff farewell**



#### Lisa Howatson Admin Support Officer

After twelve years working with ACTCOSS in office administration roles, Lisa Howatson is moving on to new horizons. We are very sad to see

her go but delighted that she found a new role that suits her talents and aspirations. Lisa has been a rock of stability, working with three Directors (Ara Creswell, Roslyn Dundas and Susan Helyar) and supporting more than twenty different staff members who have been part of the ACTCOSS team during her time. She has been the key point of contact to ACTCOSS members, people we work with in government and the private sector and members of the public who make contact with the office looking for information and guidance to the right person to respond to their requests. Lisa is kind, thoughtful and helpful – qualities that have been deeply valued in our staff team and by our members. Best wishes, Lisa, from all of us.

## **Article footnotes**

## Aboriginal and Torres Strait Islander people and intellectual disability, p. 7

1. ABS, 4704.0 - The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples, Oct 2010, 2012, accessed 30 June 2011, <a href="http://www.abs.gov.au/ausstats/abs@.nsf/mf/4704.0/>">http://www.abs.gov.au/ausstats/abs@.nsf/mf/4704.0/></a>.

2. D Griffis, First submission to the Productivity Commission Inquiry into Disability Care and Support, First People's Disability Network, 2010, accessed 30 June 2011, <http://www.pc.gov. au/\_\_data/assets/pdf\_file/0006/102795/sub0542.pdf>. 3. ibid.

4. B Fan, 'Intervention model with Indigenous Australians for non-Indigenous counsellors', *Counselling, Psychotherapy, and Health*, 3 (Indigenous Special Issue), 2007, pp. 13-20.

5. ibid.

## Learning & development calendar

Training / Forum	Date / Time	Cost: Member / Non- member / Corp. or Govt.
Reconciliation		
Aboriginal Cultural Awareness Training Facilitated by Julie Moore, Koorimunication	9 Aug 2018 13 Nov 2018 9.30am-4.30pm	\$290 / \$320 / \$350 (incl. GST)
<b>Cross-Sector Information Sessions: Aboriginal &amp; Torres</b> <b>Strait Islander Focus</b> Facilitated by ACTCOSS	30 Aug 2018 29 Nov 2018 10am-11am	Free
<b>Recognising and Responding to Trauma: Aboriginal &amp;/or</b> <b>Torres Strait Islander Children and Families</b> Facilitated by SNAICC	12-13 Sep 2018 9.30am-4.30pm	\$360 / \$385 / \$410 (incl. GST)
Reconciliation Peer Network Meeting Facilitated by ACTCOSS	20 Sep 2018 10am-11.30am	Free
<b>Strategic Indigenous Awareness: To Understand Our Present, We Must Understand Our Past</b> Presented by Grant Sarra of Grant Sarra Consultancy	25 Oct 2018 9.30am-4.30pm	\$270 / \$300 / \$330 (incl. GST)
Improving Quality & Impact of Services		
ACT Communications Peer Network Facilitated by ACTCOSS	26 Jul 2018 4 Oct 2018 2pm-3pm	Free
Leading Social Change: A Networking Event for Community Sector Board Members Facilitated by ACTCOSS	9 Aug 2018 18 Oct 2018 5.30pm-6.30pm	Free
ACT Social Enterprise Peer Network Facilitated by ACTCOSS	15 Aug 2018 12pm-2pm	Free
<b>Conscious Governance: Cybersecurity Risk</b> <b>Management Masterclass</b> Facilitated by Steven Bowman & Monica Schlesinger	28 Aug 2018 8.30am-4.30pm	\$380 / \$450 (incl. GST)
ACT Community Development Peer Network Facilitated by ACTCOSS	6 Sep 2018 8 Nov 2018 9.30am-11.30am	Free
<b>Developing Quality and Continuous Improvement</b> Facilitated by ACTCOSS	26 Oct 2018 9.30am-12.30pm	\$110 / \$140 / \$165 (incl. GST)

Find out more about our learning and development opportunities and how to register at the ACTCOSS website: www.actcoss.org.au

#### Next issue:

Update Issue 85, Spring 2018 edition

### **Housing futures**

Members are welcome to contribute articles on the theme.

#### Copy deadline: 13 August 2018

Space is limited! To guarantee your spot, let us know as soon as possible.

Email: communications@actcoss.org.au Ph: 02 6202 7200

Issue 85 will be distributed in September/ October 2018.

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Size/Type	Member	Non-member
1/4 page	\$25	\$60
1/2 page	\$40	\$85
Full page	\$60	\$120

#### **ACTCOSS committee**

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#### Vice President

Martin Fisk, Menslink

#### Secretary

Glenda Stevens, Associate Member

#### Treasurer

Lee-Ann Akauola, Relationships Australia Canberra & Region

#### **Ordinary members**

Roger Munson, ACT Advocacy Service Peter Dwyer, Religious Society of Friends Canberra Alicia Flack-Konè, ACT Down Syndrome Association Beth Slatyer, Associate Member Lynnice Church, Australia Red Cross ACT

Dalane Drexler, ACT Disability, Aged & Carer Mental Health Consumer Network Karen McKernan, Mental Health Foundation ACT Petrea Messent, Dementia Australia ACT If you would like to contact the Committee, please contact ACTCOSS. www.actcoss.org.au



The ACT Council of Social Service Inc. (ACTCOSS) is the peak representative body for people living with low incomes or disadvantage, and not-forprofit community organisations in the Australian Capital Territory.

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and/or Torres Strait Islander peoples. We celebrate Aboriginal and/ or Torres Strait Islander cultures and ongoing contributions to the ACT community.

#### **ACTCOSS**

Address:	Weston Community Hub,	
	1/6 Gritten St, Weston ACT 2611	
Phone:	02 6202 7200	
Email:	actcoss@actcoss.org.au	
Web:	www.actcoss.org.au	
Twitter:	twitter.com/actcoss	
Facebook:	www.facebook.com/actcoss	

ACTCOSS welcomes feedback. Please visit the 'Contact' page on our website for our feedback form, or contact us using the details above.

#### **ACTCOSS staff**

**Ellen Thomas** 

Director	Policy team
Susan Helyar	Craig Wallace
Gulanga Program	(Policy Manager)
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Operations team	Capability team
Stephanie Crosby (Operations Manager)	Samantha Quimby (Capability Manager)
Lisa Howatson	Ryan Joseph
Suzanne Richardson	

Update is a quarterly journal that provides an opportunity for issues relevant to ACTCOSS' membership to be discussed and for information to be shared. Views expressed are those of individual authors and do not necessarily reflect the policy views of ACTCOSS.