

National Respite Association Conference  
Tweed Heads 9-12 August.

The National Respite Association, previously Interchange Respite Association, held its 3<sup>rd</sup> National Conference last week. The two & a half day Conference maintained a strong focus on the needs of families and their sons & daughters with disability.

**What carers and care recipients said**

Delegates were introduced to some remarkable parents who had formed political parties, carer organisations and who were actively involved in the National Disability Insurance Scheme (NDIS) campaign. These parents were articulate and politically savvy and spoke not only on behalf of their own children, but on behalf of all parents and carers of people with disability.

Parents were asked about their expectations of Respite Services, Respite Coordinators and Support Workers. They wanted services to:

- ✓ Provide flexible service tailored to individual needs
- ✓ Provide consistent staff
- ✓ Provide families with information on what other services are out there
- ✓ Avoid “one size fits all” mentality
- ✓ Design activities that are fun for the care recipient

Parents wanted respite Coordinators to regard them as equal partners in the process of providing respite, to see them as the experts on their sons and daughters, and they made an impassioned plea for less paperwork. An incredulous audience heard that one parent had to complete a 100 page document! They requested thorough and accurate assessments that acknowledged the strengths of the person with disability & their family as well as their needs. They asked for a strengths based enablement approach to assessment and one which avoided the need to repeat the same information over and over again.

The characteristics that were most valued in support workers were a compassionate nature, ability to engage with the person with disability and their family, high energy levels and the ability to have fun. They valued workers who took the time to get to know the person & their family. They valued these things over formal qualifications. All acknowledged that the pay rates for respite workers did not reflect the skills needed nor the importance of the work they do.

These parents were very much in favour of individualised funding and felt that the whole system needed a fundamental overhaul such as that recommended by the Productivity Commission. The Conference delegates shared the parents’ relief that the Government had committed to the introduction of the NDIS, but we were warned that lobbying needs to continue as there is a fear that the government may “cherry pick” from the recommendations rather than embrace the whole report.

This concern was echoed by COTA Australia in their comments on the Productivity Commission report into Caring for Older Australians. COTA Australia supports the overall direction of the Report and believes it reflects what older people and their families have been saying for many years. Consumers of services for older people want

- ✓ A simple system which is easy to navigate
- ✓ Certainty – support when and where they need it
- ✓ More choice and control over services provided and by whom
- ✓ To stay in the community
- ✓ Better inclusion of carers in the support team
- ✓ Less rigidity in the system.

The current rigidities in eligibility guidelines in both the disability and aged care systems were seen as major barriers to consumer choice & innovation.

The Conference began with a parent panel and ended with a care recipient panel. The care recipients described the respite services they receive and it was clear that these services facilitated their independence and ability to contribute to the community in a variety of ways. It was refreshing to be part of a Conference where the voice of service users, their carers and families took centre stage.

### **The Koori Growing Old Well Study and Dementia Care Project**

The Koori Growing Old Well Study (“the Study”) focuses on 5 urban communities, utilising Aboriginal researchers. Even though there is still a huge discrepancy in life expectancy between indigenous and non indigenous Australians, stats for the decade 1990’s – 2000’s show that Indigenous people are living longer. As people age their risk of developing Dementia increases. A study in the Kimberley in 2008 found that Dementia was 5.2% greater in Indigenous population than non-indigenous and that acquired brain injury was 21 times more likely.

The Study grew from the work that had been done at La Perouse, looking at risk and protective factors. Asking questions such as: What leads to growing old well in Indigenous communities? Are childhood experiences an important link? The study takes a lifespan approach to wellness in older age. It is interested in finding out how many older Aboriginal people have memory problems, and dementia, what causes it, when it begins, how dementia is related to what has happened over someone’s life, and how people who have memory loss can be helped.

The early trends are that there is a greater incidence of dementia in the indigenous communities in this study. The study aims to find the preventative factors.

The learnings from this study will be applied to the **Koori Dementia Care Project**. This project is about translating the research knowledge into practice. Memory is very important for elders as they are responsible for passing on law, customs, culture – so Dementia is devastating to them and their communities. The research findings will help local communities to find the best ways of looking after older people with memory loss or dementia.

These notes have not done justice to the presentation....the major learning for me was around ethical research in Aboriginal communities, enshrining community development principles into research methodology, the importance of building relationships and trust, of taking time, acknowledging the leaders in the communities, giving ownership to the community and giving the research back in a way that enhances the well being of its members.

## **Workshops**

I attended workshops on the **new National OHS Legislation** which will be known as “Workplace Health & Safety” legislation. The new legislation will have a much broader reach than current legislation, to reflect the varied relationships in the world of work. The term employer is replaced with “Person Conducting Business or Undertaking” (PCBU).

There is a stronger focus on consultation than the existing legislation.

**Pathways in Aged Care:** AIHW research into use of aged care services before and after ACAT Assessment, found among other things that ACAT assessment was not always required, and that 19% of their sample did not use any services after assessment. I have copies of the summary reports if anyone is interested!

**Contract Law:** This workshop was delivered by an ex-contract lawyer who has virtually sacrificed a lucrative career with some of the major law firms in Oz, to care for a friend with Parkinson’s Disease. Her experience has been with Defence and Major Construction Contracts (involving \$millions++++). She reviewed the Commonwealth’s contracts with aged care providers. Her conclusions were that they were heavily biased towards protecting the Commonwealth, and that some of the clauses were ones that the companies contracting with Defence had got rid of decades ago!

**Mentoring & Coaching** A very interesting session on the Pilot being run by the National Respite Association. Claire Bishop from *Beyond Results* has developed two nationally accredited Diploma qualifications specifically for our industry – a Diploma in Community Services Coordination – Mentoring & Coaching and a Diploma in Business – Leadership & Mentoring. A panel of participants who were Managers of respite organisations spoke highly of the personal & professional development they gained from the Pilot.

**Reminiscence therapy** This workshop was close to my heart after the recent death of my father and my mother’s dementia. Bob Mitchell aka “Memory Man” works with groups of older people in various settings and also does 1:1 capturing memories of older people and recording them for posterity. [www.memoryman.com.au](http://www.memoryman.com.au) He interviews people and records their life stories on CD, sometimes with their favourite songs and photographic images. His presentation was very well received!!