PRODUCTIVITY COMMISSION – INQUIRY INTO THE DISABILITY DISCRIMINATION ACT 1992

Alice Springs visits, 24-26 June 2003 (Cate McKenzie, Patrick Laplagne, Jo Lawson)

This note was prepared by Productivity Commission staff who participated in the visit detailed below, and checked by Michele Castagna for accuracy. This note summarises the tenor of the discussions held at the time and does not represent the views of the Commission.

Alice Springs Disability Services Centre – 25 June, 1.00pm-2.00pm and 26 June, 8.00am-9.00am (Michele Castagna)

Michele Castagna (MC) has put in a submission to the DDA inquiry on behalf of the Physical Disability Council of the NT (sub. 125).

It is still an unknown quantity on how Indigenous people view disabilities. Indigenous persons often refer to disability as 'rama'. This is in relation to people exhibiting challenging behaviours that are detrimental to the community. However, people are becoming increasingly aware of disabilities in general, not just vision and hearing impairment. MC is unsure of how other disabilities are viewed. Petrol sniffing and substance abuse cause challenging behaviours that are disruptive to community and families. It is a huge issue. Many Indigenous people have become high support persons with severe multiple disabilities from constant petrol sniffing and substance abuse. It appears disabilities such as blindness and hearing impairment are well accepted, perhaps because these are part of ageing although blindness from trachoma is prevalent.

There is observed abuse of older persons, whether they have a disability or not, generally in regards to misuse of their pension monies. Other forms of abuse do exist, such as sexual abuse of both women and children, with and without disability. Many of these incidents are under reported and not addressed.

It needs to be recognised that there is a lot of good work happening through women's councils on communities in remote areas. There is still a long way to go.

Aids and equipment to assist people with disability are used by children as toys to play with and quickly becomes a wreck. Maintenance of aids and equipment is also quite problematic. Even a bush wheel chair will not last long.

It appears that disability is not a primary issue when primary health care is still lacking and high on the list of priority.

There is increased levels of hearing impairment, due to incidence otitis media (glue ear) not many Indigenous people know Auslan. Deaf children in the school system learn signing rather than Auslan as a language. This is not an alternative in Aboriginal communities as Western signing is not known. Indigenous signing can be successful in the communities. A project for Walpari signing was initiated in Tennant Creek in 1981. It was not very successful and later it was discovered they had been using men's hunting signing which is inappropriate for women to use.

Sometimes, hearing impaired people with language difficulties become isolated and finish up before courts due to their anti-social behaviour.

Some hearing impaired Indigenous people do have hearing aides and they generally get better service than the visually impaired.

Communities and Indigenous people with disability can cope with and are learning to manage disability in their own way. It is not possible due to isolation and distance and lack of infrastructure to be aware of technologies, old and new, in the communities.

Health infrastructure in the remote communities is generally limited and Home and Community Care (HACC) services struggle to provide minimum service to outlying communities.

Many Indigenous people with disabilities are not job ready and the labour market is limited. Many communities have CDEP programmes, which are often not suitable options for Indigenous persons with disability.

In remote communities, the main and major problem for people with disability is transport. The general form of transport is 'troop carriers' or utility vehicles, which are very difficult for people with disability. A troop carrier, short and long wheel based, are high off the ground and difficult to mount with a mobility restriction.

People with disabilities often have multiple disabilities. While individuals would like to remain in their communities, individuals usually have to go to Alice Springs for health care and services. This can lead to big social issues and cultural dislocation.

There are two Indigenous schools in Alice Springs; one is a primary school (Yiprinya) and the other one, Yirara, is the Indigenous high school. There are, and have been, students with disabilities at these schools. Originally, no extra support was provided to these students without a fuss being made. Support was eventually provided under threat of the Disability Discrimination Act, which has proven a powerful ally in addressing such matters.

People with disabilities generally want to stay in their communities. There are often problems if their extended families come into Alice Springs with them because of overcrowding of relatives' homes where they stay.

Indigenous organisations do require more education about the DDA as there is a lack of knowledge and understanding of the Act and consequently little use is made of it's intent to improve a person's lifestyle.

Before the DDA, disability advocates had to rely on goodwill and bluster. MC hopes that the disability discrimination situation may improve once the Indigenous Disability Network initiative takes off and becomes well known.

MC is concerned that the States and Commonwealth are shifting responsibility between each other for funding especially in the unmet need arena.

MC believes there should be a specialised disability discrimination commissioner at HREOC particularly due to the education and awareness function of the commission. The HREOC disability commissioner needs to be autonomous and independent of government so that s/he can call the government to task. MC believes government should be a model employer and service provider, thus setting the benchmark.

A new programme is the Multidisciplinary Accelerated Rehabilitation Service (MARS). However, it has had a slow pick up. There are few specialists/therapists in Alice Springs and even less in the remote communities. Most are private and expensive, which can be very difficult for Indigenous and low income people on a disability pension or other benefits to access.

(Material below is from second visit to MC)

It would be helpful if HREOC had the power to initiate complaints, especially on behalf of Indigenous people, and people from culturally and linguistically diverse backgrounds. While there are many disability assistance mechanisms available, people with disabilities need to be made aware of them and empowered.

Disability is very low on the Indigenous ladder, with little specific time devoted to this issue. This has led Indigenous organisations to concentrate on the medical model of disability, which is well known. We need to move away from this model and encourage people to understand the community developmental models.

The creation of the Indigenous Disability Network could assist in forging links between disability organisations and primary health care providers, who don't always know where to start with disability. Money isn't always the problem. The network would/could provide a voice for Indigenous people with disability and encourage the community development model.

Many Indigenous communities don't want people with challenging behaviour, as it is too difficult and disruptive to manage. However, some communities such as Santa Teresa are achieving good results due to a pilot programme of

community capacity building that included the community council, the peoples and the youth with disability. The creation of a disability-specialised position on the community has helped change community attitudes. There has also been some useful work at the Yuendumu community, with the Women's Council helping with meals, washing, collecting firewood, etc. Mutitjulu, past Uluru in the Pit Lands, has a struggling respite care service.

However, most communities struggle just to preserve access to basic amenities such as water and electricity, so that disability is low on the scale of priorities.

Housing is often not designed or accessible to meet Indigenous requirements. For example, the need for large cooking and communal spaces rather than individual bedrooms. Many individuals prefer to sleep outside under the stars.

While Indigenous youth don't necessarily want to come to Alice Springs, there is not enough to keep them occupied on remote communities. The consumption of alcohol, cannabis, etc. leads to the breakdown of social mores. In general, however, community ties remain very strong, which can lead to huge problems of dislocation when a member has to come to Alice Springs. A lot of people with severe disabilities are admitted into nursing homes at an early age, thus losing community contact and dying prematurely.

MC provides a number of services to people with a disability, on behalf of the NT Department of Health and Community Services and has a regional responsibility that includes Tennant Creek and Barkly. She does in-service and community training and provides information and referral services. MC also increasingly does access audits for the public and private sectors in relation to the built environment. This has led to public buildings (eg. jail) being fully accessible. Others, such as the court house, which is semi accessible, results in discrimination against people with disability in jury selection and in being able to do one's civic duty.

In the private sector, many doctors' surgeries are not able to cater for people with disabilities either in the entry of building or surgery sized rooms and patient examination tables. Breast screening and pap smears as preventative health are difficult to access.

The MARS scheme funds the provision of private allied services to people with disabilities via referral from GPs. When accessed, this service works well because the public health system is overworked. However, not enough GPs know about MARS and, when they do, they don't like the extra administrative load of referral. Again, there is a problem with providers knowing what options are available.

The DDA's exemption of small planes from transport standards creates problems in remote communities. It is very difficult to safely and securely transport people with mental and/or physical problems by air. Individuals have to be driven, often over very long distances and rough roads. A programme called Patient Assistance Transport Scheme (PATS) funds the air

transport of patients to Alice Springs or Adelaide, if they are far away or services are not available in Alice Springs. The PATS scheme however can rely on an upfront payment by the patient and a subsequent refund. Patients are often out of pocket, especially in terms of accommodation where the pay rate per day is extremely low and has not kept abreast with inflation rates.

Accessible transport issues also arise in the tourism sector as currently no tourist coach or bus in the NT is yet compliant with the DDA Transport Standards. Tourists with disabilities have to incur the extra cost of taxis ($100 versus $43 on some destinations). On the positive side, public transport in Alice Springs is fully accessible.

While communications in the bush remain a problem, things are better where nursing clinics and community councils exist. These are generally equipped with computers, but they are heavily used. Use for education or community services purposes is difficult or simply does not happen.

Accessibility continues to remain a problem for independent schools. Post-construction modifications are very expensive, and Government funding is limited or non existent.