

**Full and Final Report to AFDO**  
**on**  
**Consultations for National Disability Strategy**  
**Rural NSW area**  
**by**  
**Sue Egan - AFDO Board member**

The writer of this report, Sue Egan is the Executive Officer of Physical Disability Australia, and a board member of AFDO. AFDO supplied funds (through the Department of Families, Housing, Community Services and Indigenous Affairs - FAHCSIA) for consultations. For the purposes of this report these consultation workshops were held in rural NSW in the following 4 areas:

When: 12th November - 1 - 4pm

Where: GLENROI COMMUNITY CENTRE  
Gareema Road, Orange

When: 18th November - 1 - 4pm

Where: COFFS HARBOUR COMMUNITY VILLAGE  
22 Earl Street Coffs Harbour.

When: 19th November - 1 - 4pm

Where: GRAFTON COMMUNITY CENTRE  
59 Duke Street Grafton

When: 20th November - 1 - 4pm

Where: GOONELLABAH COMMUNITY CENTRE  
27 Oliver Street Lismore.

**1. Orange - 12th November.**

The first workshop was held in Orange in central western NSW. This is a large city by country standards with over 40,000 people. Situated in the central west, Orange is noted for its apples (not oranges) and surrounding wheat and sheep as well as forest industry nearby.

The workshop itself was held at Glenroi Community Centre and the participation rate was 23 people from a variety of areas as wide as Dubbo, Bathurst, Mudgee and other surrounding towns.

The attendees represented:

- Support persons including interpreter

- Parents of children with disabilities
- Child with a disability
- Service personnel
- Government Departments (state)
- Individuals with a disability

The facilitator (Sue Egan, assisted by Sam Peterson - note taker) spoke about the National Disability Strategy, the initiative from the Federal Government and the funds supplied for consultations, and the reasons for travelling to rural areas to engage that sector of the community. This format was followed through at all four workshops.

This was followed by an introduction of self, by all members of the audience and followed by their stories and issues, most of which were written down.

This report contains those issues not prioritised but all equally important as verified by those present:

- ◆ Access to premises
- ◆ lack of local accessible transport
- ◆ Cost of Disability for individuals and for parents
- ◆ Accommodation and housing options are non existent
- ◆ Support in accommodation
- ◆ Lack of Peer support resources
- ◆ Equipment (in this case NSW PADP scheme)
- ◆ Informal networks for Parents and those who care for people with disability
- ◆ Training for people with disability and parents in computers
- ◆ Supply and availability (cost) of computers for information and communication
- ◆ Respite - lack of funding and availability
- ◆ Disconnected government services (both state and federal)
- ◆ Recreation activities for children with disabilities
- ◆ Lack of Advocacy services in the area
- ◆ Centrelink, attitudes and help
- ◆ Underfunding of good services such as DIAS
- ◆ Inequality of fund distribution
- ◆ Service Provider training and attitudes
- ◆ Lack of flexibility in service delivery
- ◆ Lack of specialist medical services in the country
- ◆ PBS - drugs
- ◆ Distance to other resources
- ◆ Education and shifting responsibilities
- ◆ Rights education
- ◆ Discrimination at all levels
- ◆ Myths and conceptions about people with disability
- ◆ Large waiting lists for everything
- ◆ Lack of employment options
- ◆ Carers and DSP payments too small
- ◆ Parents of children with disabilities is full time work
- ◆ Limited Bulk Billing with Doctors in rural areas.

## **2. Coffs Harbour NSW - 18th November.**

The second workshop was held in Coffs Harbour Community Village in the Mid North Coast of NSW. Coffs Harbour is traditionally a tourist mecca, being swamped with holiday makers particularly during the summer periods.

The workshop was held at Coffs Harbour Community Village, and the attendees numbered 22.

The same format was presented as in Orange. Participants included:

- People with a disability (the majority)
- parents of children with disability
- Partners of people with disability
- Support workers from service organisations
- Interpreter

The issues were almost the same as in Orange with a couple of additional items. These included the following:

- ◆ Home care services
- ◆ Access to premises
- ◆ Public transport
- ◆ Disability Parking
- ◆ Employment discrimination and lack of options
- ◆ Cost of Disability
- ◆ No tax concessions for equipment essentials
- ◆ Veterans Affairs have different systems for same issues
- ◆ Government Departments not communicating with one another
- ◆ Stigma and attitudes
- ◆ Lack of affordable and accessible accommodation options including motels and hotels
- ◆ Waiting lists for services in the country
- ◆ Equipment and prosthetics is going backwards.
- ◆ Mobility allowance restrictions and differences in amounts for seeking work and working
- ◆ Interpreter shortage in community, hospitals, schools
- ◆ Captioning services needed
- ◆ Mental Health services non existent in rural areas
- ◆ No continuity of medical personnel
- ◆ Medical care is lessened and limited
- ◆ Bulk Billing limited
- ◆ Bus companies charging more for accessible buses
- ◆ Therapist shortages in rural areas and services limited
- ◆ Cut off points in services as in children versus adults.
- ◆ Human Rights Australia is a toothless tiger
- ◆ Cost of disability in daily living
- ◆ Disincentive to work if partner works
- ◆ Homecare restrictions and hours
- ◆ Lack of experience in 'Allied Health' personnel especially in disability
- ◆ Disability services seen as a 'cash cow' but most spent on administration
- ◆ No personal care for those over 50 years old
- ◆ Dollars spent in rural areas are much less than in cities
- ◆ Private certifiers signing off on access to premises to new buildings which are not

accessible.

- ◆ MLAK system of key distribution needs to be more formalised and recognised
- ◆ Cost of vehicles that can carry electric wheelchairs for families and people with disability who drive and use an electric wheelchair.

### **3. Grafton - 19th November.**

The third workshop was held in Grafton in the Northern Rivers area of NSW and covers the area to the NSW border with Queensland.

The number of attendees at this workshop was 12 and consisted of:

- Service workers
- Individuals with all types of disability
- Interpreters
- Government Departments - Federal and State

The issues raised at this workshop included the following:

- ◆ Lack of awareness of disability and recognition as a person in their own right
- ◆ Transport and school holidays mean no buses running as usual
- ◆ Access to Premises
- ◆ Lack of opportunities for weekend activities for people with disability
- ◆ Employment discrimination and lack of opportunities
- ◆ Centralised services means limited access to services
- ◆ Long waiting lists for allied health services
- ◆ No specialists in country areas
- ◆ Paying costs upfront for medical and allied treatments
- ◆ Lack of awareness, education on disability of doctors
- ◆ No specialists in country areas
- ◆ Lack of supported accommodation and housing options
- ◆ Limited respite available
- ◆ Parents of children with disabilities unable to work because of child's needs
- ◆ Funding guidelines for services often not aligned to rural reality
- ◆ Centrelink is a minefield
- ◆ Centrelink reviews unnecessary for those with permanent disability.
- ◆ Isolation and high cost of travel to cities
- ◆ Parking for people with disability
- ◆ Public education and awareness needed
- ◆ Airlines in rural areas
- ◆ Access committees not consistent across the State
- ◆ Long waiting list for services of any kind
- ◆ Nursing homes the only option for many people with disabilities .
- ◆ Most of the funding is chewed up by travel kilometres and administration
- ◆ No peer support options
- ◆ Education and re-education is too expensive and first steps are too high for beginners
- ◆ No small training options available such as skillshares and Job Clubs for employment
- ◆ Red tape delays and accountability too detailed and delays processes
- ◆ Waste of money on administration and impacts on the service delivery

- ◆ Lack of information on what is available to people with disability
- ◆ More research needed in disability specific areas
- ◆ Services double up and 'pick and choose' clients
- ◆ Equipment waiting lists can be to 2 years in some areas, more in others.
- ◆ Lack of housekeeping resources and services
- ◆ Services and specific requirements impacting on cost of disability
- ◆ Ageing parents going into hospital leaves people with disability exposed and vulnerable.
- ◆ Attendant care not transferable across State borders
- ◆ Hospital to home waiting lists are huge
- ◆ No services except respite if no home based support is available.
- ◆ Need individualised funding
- ◆ Need more co-operation between services
- ◆ Tailored programmes no longer exist

#### **4. Lismore - 20th November.**

The Lismore workshop was held at Goonellabah Community Centre and was attended by 20 people. This included:

- People with disability
- Partners and family of people with disability
- Service workers

The issues presented at this workshop included:

- ◆ Cost of Disability
- ◆ No specialist services between Tweed Heads and Port Macquarie
- ◆ Lack of Doctor knowledge about disability issues
- ◆ Medications in hospital and change of regime and resulting impact
- ◆ Public hospital systems not flexible and the need to self regulate
- ◆ No specialist services between Tweed Heads and Port Macquarie
- ◆ Lack of Doctor knowledge about disability issues
- ◆ Medications in hospital and change of regime and resulting impact
- ◆ Public hospital systems not flexible and the need to self regulate
- ◆ No communication between hospitals and General Physician
- ◆ Red tape and expense in being assessed for drivers license
- ◆ Doctors not qualified to assess for ability to drive
- ◆ General perception is of disability not the person
- ◆ Multiple 'small' disabilities not recognised as a disability so limited support
- ◆ Homecare and Respite services do not extend to childcare for mothers with disability
- ◆ Assessment guidelines are too narrow because of lack of funds
- ◆ Specialisation in all areas of service lead to duplication and exclusion
- ◆ Need standardised Assessments across Australia
- ◆ Self managed funding
- ◆ Need National Database of services for all stakeholders
- ◆ Equipment
- ◆ Transport
- ◆ High and complex needs of people with disability put in the 'too hard basket'
- ◆ Accommodation and Housing shortages

- ◆ Access to premises
- ◆ Centrelink attitudes
- ◆ lack of experience in disability by all professions
- ◆ Many do not qualify for DSP and therefore have no supports
- ◆ Health Care Card needed for people with disability to work
- ◆ Impossible to get repairs done locally to equipment
- ◆ Regional issues have greater issues but less funding
- ◆ Decision making seems to be at a standstill
- ◆ Inappropriate referrals
- ◆ Very long waiting lists for referrals to specialists
- ◆ Lack of knowledge of ADD, ADHD, Aspergers and also Mental Health issues
- ◆ Cutting of funds for education - less options
- ◆ No support for distance education for people with disability with learning disabilities

## **OVERALL RECOMMENDATIONS**

**ACCESS TO PREMISES** is almost universal in its lack of inclusion. People at all workshops raised this issue and discussed it at length. Access to premises affects almost all people with disability in some way, whether it is signage, accessways, space, getting into a building, audio loops and many other ways.

The issues raised from the workshops included many perspectives of how access to premises excludes people in their community. The writer of this report also noted how some areas of rural communities were did not comply with the DDA or existing Building Codes and the opinions were consistent in that overall councils do not seem to be consistent in their approach to access.

The motel and accommodation inadequacy was experienced by the writer in travelling to conduct these workshops. This impacts on the tourist industry and hospitality industry of rural areas, which depend on the many varieties of income for sustainability in the country areas of Australia.

There are Private certifiers signing off on access to premises to new buildings which are not accessible. Private certifiers appear to have less information about legal requirements under the DDA for access to premises.

The MLAK system of key distribution for accessible toilets across the country needs to be more formalised and recognised nationally

**Recommend** that the Access to Premises Standard be finalised immediately and implemented as soon as possible to ensure there is consistency for all stakeholders including Councils in the approval process, builders and developers in understanding what is required and the prevention of exclusion and discrimination for the future.

### **Access Inclusion in the National Disability Strategy:**

*Access to Premises is the right of every Australian. Ensure it is the right of those who have a disability also, as it is the pathway to inclusion in society.*

*Investigate the reasons why the Access to Premises Standard is taking so long to administer and implement.*

*Address the contentious issues in a way that is inclusive of people with disability today*

*and in the future, without funding being the reason why it is not provided as the benefit of providing inclusion to all citizens is immeasurable.*

*Ratification of the DDA Access to Premises Standard immediately*

*Develop the MLAK key distribution system to streamline and have national guidelines.*

**ACCOMMODATION AND HOUSING OPTIONS** are non-existent in rural areas with waiting lists of years and years with little public housing options being built. Rents are exorbitant out of a Disability Support Pension and the supply of accessible accommodation options is minute.

Many people with disability in remote areas are restricted to living at home with ageing parents because there are no other options available to them.

**Recommend** that more public housing and associated infrastructure be built in rural and remote areas to meet the demand for housing in these areas. All housing should be built using Universal Adaptable Housing methods, to meet both the need for people with disability and their families, and the future ageing population of Australia.

**Recommend** a home buying assistance programme nationally, so that those on the lower socio-economic strata can afford their own home over the period of their life.

#### *Accommodation and Housing inclusion in the National Disability Strategy.*

*A commitment to providing public housing for those most vulnerable, people with disabilities. This would also benefit those who are homeless, the ageing sector and others. In addition a commitment to developing a Home Buying Assistance Programme to enable those who have lesser incomes to purchase their own home of their choice.*

**ACCOMMODATION SUPPORT** is also in demand and there is not enough dollars supplied by either State or Federal government to meet the demand or hours of support needed.

**Recommend** that funds be increased at all levels (Federal and State governments) to meet the demand for support to live independently in own homes or in public housing. This would enable more people to live in the community, engage in employment, training, voluntary work, recreation and other community activities.

#### *Support in Accommodation inclusion in the National Disability Strategy.*

*Accommodation support, Personal Care and Attendant Care should be addressed and allocations of funding increased to enable all people with disabilities to live in a home of their choice as independently as possible.*

#### **AIRLINES IN RURAL AREAS**

Airlines in rural areas continue to discriminate against people with disabilities by not allowing those with wheelchairs to fly in smaller planes, which is often the only and quickest way to get to Specialists and Treatment in major cities.

There is a great deal of research and case studies available to confirm this discrimination and people therefore felt it was time for the Federal Government to step in and make the system

more accountable to the DDA (1992).

### **Recommend**

That a National Air Strategy be implemented, with the strategy addressing the continued and advancing discrimination against people with disability.

### **Airlines in rural areas inclusion in the National Disability Strategy.**

***National Disability Strategy to include a National Airline travel and Public Transport component in line with the DDA and the UN Convention on the Rights of Disabled Persons.***

**AWARENESS RAISING.** The general perception in the community, is considered to be of the disability first and not the person first.

There is also an area of disabilities that are not recognised as disability and therefore receive little or no support in the way of funding.

There is an enormous lack of knowledge of disabilities such as ADD, ADHD, Aspergers and also Mental Health in the community.

There is a general lack of awareness and understanding that underneath every disability there exists a person first and foremost.

### **Awareness raising in the National Disability Strategy.**

***Develop an awareness raising campaign for distribution in the community to encourage the philosophy that we are people first and foremost and that our disabilities are external to the personal and something that we live with. Society creates the barriers, and excludes us because of our disability and these need to be eliminated to create full inclusion for all.***

**CENTRELINK** was raised many times by participants in workshops as having extreme attitudes which could be considered abuse by some. Many people experienced bad behaviours by staff of Centrelink and for most a simple request resulted in the person receiving comment as if some in Centrelink believed the funds came from their own pockets.

People reported that it was a minefield to go to Centrelink as there are pervading attitudes that people with disability are phoney and pretend their disability in order not to work!

Others reported that many people do not qualify for a DSP and therefore have no income support or at least Newstart especially under the previous policies of government.

**Recommend** Staff training at all levels of Customer Service on Disability Awareness and **Manners**, ensuring that staff realise they work for the public and the general public regardless of situation deserve to be treated with respect.

### **Centrelink in the National Disability Strategy.**

***Staff at Centrelink should be trained in Disability Awareness and courtesy to all potential and current clients and more people with disability MUST be employed by***

*Centrelink.*

*A public recruitment drive of people with disability to work in Centrelink in front line roles to show the committment of government to working with and for people with disabilities.*

***COST OF DISABILITY*** for individuals and for parents is and was, an enormous issue. Costs ranged from equipment, medications, housing and or rents, taxis, cooling in summer and heating in winter (rural areas can be extremely hot in summer and cold in winter). The cost of respite, Home Care, additional personal support, modifications to homes, computers and internet (essential for isolated and rural people with disability). In addition people with disability who needed to visit specialists and Allied Health experts in cities requires travel, accommodation overnight at least, additional food and other items. The current allowance pays only \$30 per night for accommodation, Drs often do not bulk bill so payment up front is required. These are only some of the extra costs of disability.

**Recommend** that a Disability Allowance be implemented as soon as possible, non means tested, available to all persons who have a disability regardless of status, situation or living situation, to meet these additional costs.

**Recommend** that an appropriate Travel and Accommodation Allowance be available to those who require travel to cities for medical care and treatment.

**Recommend** that the Mobility Allowance be equal across all those who are eligible rather than those seeking work who receive \$100 per fortnight and those in work (or not seeking work) receive around \$76.50 per fortnight, when the travel costs are the same if not more.

**Cost of Disability inclusion in the National Disability Strategy.**

***A cost of disability Allowance implemented to meet the needs directly associated with having a disability over and above the daily cost of living.***

***This Allowance should not be means tested, be payable to anyone with a disability regardless of employment or economic status or marital status. The Allowance should be paid directly to the person with a disability, or in the case of a child, to the parents.***

***Increase the Mobility Allowance to be equal across all eligible recipients.***

## **DISABILITY SUPPORT PENSION**

Almost all participants agreed that the DSP does not meet everyday financial need to cover rents, mortgage payments, food, power, and all other essentials.

**Recommend** that the Disability Support Pension be increased immediately to ensure that people with disability do not have to live in poverty as they have been.

**Disability Support Pension inclusion in the National Disability Strategy.**

***Provision for Income Support, to ensure that Pensions and relevant allowances are kept in line with inflation on a regular basis and addressed/reviewed at regular periods of time.***

## DISCRIMINATION

People at all workshops described discrimination taking place at all levels of society. Many believed that the DDA (1992) is not strong enough to deal with the discrimination that takes place, and that people in general are ignorant about disability reality with many myths and misconceptions about people with disability.

People also believed that the Human Rights Commission (formerly HREOC) is a toothless tiger with many complaints unsuccessful, therefore discouraging people to complain. This is especially so for complaints that should go to the Federal Court as most people with a disability cannot afford to risk their homes or other assets to fight a complaint against large businesses who have Lawyers and Queens Counsels at their disposal.

In the past few weeks the Human Rights Commission revealed that the number of complaints were up in numbers, which says that discrimination is out there and alive and well. This will continue to happen unless governments decide to address this in a more systemic way, by strengthening the DDA itself and the relevant compliance methods.

**Recommend** that the DDA be strengthened to ensure that it is in line with the UN Convention on the Rights of Disabled Persons at all levels, since Australia is now a signatory.

***Discrimination inclusion in the National Disability Strategy.***

***A National Disability Strategy that is framed within the UN Convention on Rights of Disabled Persons and to confront Discrimination head on, and eliminate as much as possible the exclusion of people with disabilities.***

## EDUCATION

Australia has a DDA Education Standard, much to the surprise of many people who have children with disabilities.

During the workshops it became obvious that some schools also prefer not to have knowledge of the Education Standard with some stating outright that they will not take a child with a disability because they have no resources.

Other comments from participants included:

- Education Department and schools are shifting responsibilities on to parents and/or service providers instead of addressing the issue of educating children regardless of disability.
- What is needed is some Rights Education for parents and educators
- Cutting of funds for education means less options to educate our children
- No support for distance education for people with disability and those with learning disabilities
- Education and re-education is too expensive for those on a Disability Support Pension and often the first steps to further education are too high for beginners.
- No longer any small training options available such as skillshares and Job Clubs for employment preparation.

**Recommend:** That promotion and knowledge of the DDA Education Standard MUST be circulated to schools and all education facilities.

**Recommend:** Training for Teachers and other staff in relation to disability Awareness

**Recommend:** Training in Discrimination for teachers and staff in relation to disability

**Recommend:** An Education Strategy in line with the Pathways Education Strategy

**Education inclusion in the National Disability Strategy.**

***An Education Strategy for children and people with disabilities included in the overall National Disability Strategy addressing many of the issues raised in these consultations.***

**EMPLOYMENT**

Employment was raised on numerous occasions at all workshops. The problems facing people with disability in rural locations included:

Lack of employment options in rural towns and surrounding areas

Employment discrimination is rampant

Parents of children with disabilities already have a full time job, looking after their children's needs and have no time to take on outside work especially when there are so few options.

Lack of access to businesses, because of inaccessible premises

No reliable and regular transport system to enable work participation, and would have to rely on taxis (discussed elsewhere) to get to and from work, which will impact on Income support and incentive.

**Recommend** That the Employment Strategy (previously developed by Government through consultation) be part of the National Disability Strategy and addresses many of the issues described by people with disability as preventing them from working in the real world.

**Employment inclusion in the National Disability Strategy.**

***Include an Employment Strategy as part of the overall National Disability Strategy.***

**EQUIPMENT** (in this case NSW PADP scheme). This was an issue raised at all workshops, whether parents, support persons or individuals with a disability. The PADP scheme and others around the country are not working in favour of those who rely on equipment such as wheelchairs, walking frames, surgical boots and calipers, prosthetics and other essential equipment for daily usage and survival.

In addition there are no local resources for repairs of equipment because of the constraints of procedures in the Equipment Scheme (PADP)

Equipment is the lifeline between inclusion in society or exclusion and isolation. Without the appropriate equipment people with disabilities will not progress in society. To deny a person essential affordable equipment is sentencing many people with disability to remain at home, inactive and isolated.

**Example:** A child we will call Sarah, is 8 years old and lives in a small rural community with her mother and siblings. Sarah has Cerebral Palsy and uses a wheelchair permanently. She is unable to use verbal communication and uses a speech activated computer and has a manual

wheelchair and attends a public school.

Sarah's mother Christine (names changed for privacy) has applied for and been waiting several years for an electric wheelchair for Sarah, which would enable her to be more active at school with her friends and be more independent than she is. This would also free up Sarah's mother from having to push Sarah everywhere as she is unable to use a manual wheelchair herself. Sarah has a highly active mind and is very intelligent and without the use of an electric wheelchair and an up to date communication system she will flounder and the opportunity for a bright child to advance, will be lost.

**Recommend:** That the equipment schemes in Australia be amalgamated into one system (A National System) that is realistic and up to date on the equipment supplied, timely in response for requests for new equipment which enables people with disability to be equal to their peers, and especially addresses the needs of our children with disabilities.

Equipment such as crutches, wheelchairs of all types, walking frames and other mobility devices are not luxuries, they are our feet and legs and essential for mobility of any kind. Equipment used for communication purposes is essential to inclusion in society and being able to be educated, being employed and live in the community generally. The system reported to the writer was also that hearing aids are free up to the age of 21 and thereafter must be paid for. This is not equitable with adults with disabilities. The disability does not diminish or vanish after age 21 or for those who turn 65 years which also requires a change of programme.

**Recommend:** Governments need to recognise that the Equipment Schemes in rural areas are not working effectively and to the disadvantage of those who need equipment. This is an urgent situation that needs to be addressed and rectified immediately.

Recommend: Governments enable local trades to repair equipment when needed in the case of rural and remote areas instead of having to send equipment to Sydney.

### *Equipment inclusion in the National Disability Strategy*

*A National system of Equipment purchase and distribution is urgently needed, regulated by Government with a national reference group consisting of people with disability and other experts in the field.*

*Research and development of equipment such as wheelchairs, surgical equipment, communication needs and more, should be implemented immediately to create an Australian base and supply of equipment rather than the costly equipment that comes from overseas.*

*A national reference group consisting of people with disability and other professionals to oversee the administration, policies and practise of a National Disability Equipment Scheme.*

### **INDIVIDUAL FUNDING**

Individual Funding or Self managed funding was put forward by participants as the way of the future. This was seen as more equitable, diminishes the enormous costs for administration taken by services and allows more flexibility and empowerment of the individual with a disability.

**Recommend** That Government invest in Individualised Funding so that people with disability

are in control of their own lives and future.

The system could use a 'Debit Card' supplied to all people with a disability eligible for Individualised Funding, with funds being transferred onto the Debit Card and to be used similar to a 'Barter Card' exchanging funds for services.

Determining the amount of individual funding would be done based on need and timeliness, with an overall supervisory mechanism in place to ensure the funds are used appropriately.

In the case of children with disability or those who are unable to manage their own funds, parents and/or guardians would be responsible for the card and for the services used.

Other programmes could be integrated into this system such as CASS, and Equipment (from a National Scheme) Attendant Care, Personal Support, Accommodation etc which would enable to individual to (a) 'shop around' for the best service, and (b) makes services more accountable to the consumer and to government.

### **Individual Funding inclusion in the National Disability Strategy.**

*The Strategy include provision for moving toward Individual Funding, with a national Reference Committee overseeing the administration and progress of the programme.*

*All reference committees set up under the Strategy, MUST have a majority of people with disabilities as members of the committees.*

**INFORMAL NETWORKS FOR PARENTS AND THOSE WHO CARE FOR PEOPLE WITH DISABILITY.** Not all people who support people with disability are in the Carer Loop. Many parents do not agree with being called a carer and prefer to be considered as the parent of a child with a disability. Many of these same parents experience isolation from their remote locations.

**Recommend** that a system similar to the Peer Support system mentioned elsewhere, could be initiated with cheaper computers and internet which will go some way toward meeting the isolation and remoteness of parents of children with disability.

### **Informal Networks for Parents and those who care for people with disability in the National Disability Strategy.**

*Develop a nationwide programme (with the assistance of National Families organisations through their memberships and Disability organisations) to address the isolation of parents of people with disability in rural and remote areas to enable them to seek information and resources and to communicate with peers and the wider world. This would be an investment in the future and enable more people to learn online, work online and at home whilst taking care of their children and thereby create a more accessible world online.*

**MEDICAL AND HEALTH** was a huge issue for all participants many of whom had progressive disabilities such as Multiple Sclerosis, Parkinsons Disease, Diabetes and more.

All persons reported problems with the medical system in rural areas, including:

- ◆ Lack of specialist medical services in rural areas resulting in long trips (unfunded often) to access services. It was reported that there are no specialist services between Tweed Heads and Port Macquarie on NSW Coast, for example.
- ◆ Doctors are used as experts on whether a person with a disability should be able to drive, yet they often do not know the person or their ability and therefore are not qualified to assess for ability to drive.
- ◆ All persons felt that there was a lack of knowledge about disability issues across all medical disciplines.
- ◆ Some reported that once admitted to hospital, your own medication regime is ignored in hospital and a change of regime has an enormous impact on day to day health and response.
- ◆ Public hospital systems are seen as not flexible and the need to self regulate treatment and medications is completely ignored.
- ◆ There is no communication between hospitals and General Physician, who looks after the person on a regular basis, and this was felt to be essential for good healthcare.
- ◆ PBS - drugs are often prescribed that need 'red tape reporting' which means that they are expensive and often not recommended because of the extra workload they carry for Doctors.
- ◆ The Health Care Card (HCC) is vital for those with medication needs such as MS, Spinal Injury, Diabetes and more and without a HCC the prospect of working is diminished as many cannot afford the medications to keep them healthy and active in a working life.
- ◆ There are very long waiting lists for referrals to specialists and for allied health services
- ◆ It was felt that there was a general lack of experience in 'Allied Health' personnel especially in disability and especially among those just out of University with no life or working experience yet they are making decisions about the lives of people with disability.
- ◆ There is no continuity of medical personnel and it is more of a 'here today, gone tomorrow' type of system. No continuity of care and medical care is lessened and limited
- ◆ Bulk Billing is extremely limited with more and more professionals preferring cash up front. Often people with disability do not have the money up front, so will avoid going to doctors or medical practitioners and thereby risking their health.
- ◆ Therapist shortages in rural areas and services are also limited

Recommend that a National Inquiry be set up to investigate the shortage of Doctors in rural areas as well as all Allied Health Professionals, with financial education incentives to study in these areas, and serve an 'Apprentice or Cadetship' in rural areas as part of the 'repayment' of the subsidised study.

These are essential services and communities cannot do without them. Communities will be seriously in trouble if these shortages and lack of services are not addressed, along with the inappropriate attitudes and lack of knowledge on disability. It is felt by the writer that these issues impacting on disability are probably impacting in much the same way on the overall community.

**Medical and Health inclusion in the National Disability Strategy.**

*A national inquiry into the shortage of medical professionals to identify where and how the shortages arise.*

*The national inquiry should also investigate how much education and knowledge medical professionals receive regarding disability and if it is found to be limited then the curriculum addressed by the University Bodies with the view to improving education. One way of doing this could be to have an additional course before taking on rural or remote positions.*

## **PARKING FOR PEOPLE WITH DISABILITY**

Parking problems are universal with few councils taking on the monitoring and addressing of parking 'theives.' Participants agreed that what is needed is a National Permit Parking Scheme, that is nationalised and administered by government under Transport and Policing.

All agreed that there need to be public education and awareness on why people with disability need permit parking and why wider bays are necessary for parking. It was also felt that this should be portrayed as rights based, rather than a nice thing to do for people with disability.

It was also felt that shopping centre managers should be made more responsible for monitoring parking, and also those whose businesses have allocated disability parking should be encouraged to understand their responsibility and report abuse.

Doctors and medical professionals are also guilty of signing forms for permit parking when under the current guidelines, these people should not be issued with parking permits.

**Recommend** A public education programme to ensure that parking thieves understand there are liabilities for parking in designated spaces, and that people will be charged for abusing the system.

**Recommend** An education programme for medical professionals who sign forms permitting many with the smallest of disability to get parking permits, when they were intended in the first instance for those who had difficulty walking and needed to be closer to doorways and entries.

### **Permit Parking inclusion in the National Disability Strategy.**

*A national Permit Parking Scheme administer by the Federal Government with a National Reference Group working with both Department of Transport and the Police Department.*

*A system of fines and follow up that ensures that abuse diminishes because of the level of fine.*

*A public education campaign to ensure the general public actually understands the need and 'gets the message' that parking in those spaces is for people with disability who cannot walk only.*

**PEER SUPPORT** was one of the issues raised by all areas of disability especially those who are under 40 years of age. The writer suspects that this is an issue that is enormous in the rural and remote areas of Australia. Empowerment comes from sharing information and

advise and stories, and because there are so few people who can afford a computer and an internet connection. It has already been published that the Internet and a computer is the largest and simplest method of including people with disability in the world.

**Recommend** that there be funds and a scheme set up to enable rural and remote people with disability to have a computer (second hand from Green PC, government or similar) and a connection to the internet to enable easy communication and resource searching.

**Peer Support Programmes inclusion in the National Disability Strategy.**

*Develop a nationwide programme (with the assistance of National Disability Peak organisations through their memberships) to address the isolation of people with disability in rural and remote areas to enable them to seek information and resources and to communicate with peers and the wider world. This would be an investment in the future and enable more people to learn online, work online and at home (as the writer does) and thereby create a more accessible world online.*

**RECREATION, THE ARTS AND SPORT**

Lack of opportunities for weekend activities for people with disability

Recreation was an area that sparked a great deal of interest from people in rural areas, as there appears to be few options at the local level. On weekends there is little to do or become involved in for people with disabilities as most programmes are operated during the week, where there are any.

Parents of children with disabilities reported that there were few if any options for their children to be involved in sport or recreation after school or on holidays and weekends.

**Recommend** that an investigation be carried out, into the recreational, art and sport opportunities as they apply to the rural and remote areas, and that more fund be granted specifically for adults and children with disability to become involved in cultural and artistic pursuits as well as local sport opportunities.

**Recreation, The Arts and Sport inclusion in the National Disability Strategy.**

*The National Disability Arts Strategy be included as part of the National Disability Strategy and that government Departments ensure that people with disability become part of the process addressing rural and remote areas also.*

**RESPITE** was raised at all workshops as a critical issue in the rural areas of NSW. There is a shortage of respite options for people with disability, parents with disabilities, parents of children with disability and others.

Respite is often costly, not easily accessible in locations and the older generations often take priority. The alternative is hospitalisation in a nursing home for those with a disability.

At best Respite across Australia is a piecemeal approach and there is no consistency from one establishment to another. This needs to be consistent for all users and prospective users.

**Recommend:** That government investigate where respite centres are located and ensure that there is adequate coverage across the nation.

**Respite in the National Disability Strategy.**

***Develop a National Respite Programme to ensure equity, costs, availability and administration to ensure that respite is available to those in immediate or temporary need of respite including respite FOR people with disability and not the supporting persons.***

**SERVICES (BOTH STATE AND FEDERAL)** elicited the most comments of all, with many disparaging remarks, indicating the level of dissatisfaction with services across State and Federal Governments. The comments included:

- ◆ No recreation activities for children or adults with disabilities in rural areas.
- ◆ lack of Advocacy services in the area
- ◆ Underfunding of good services such as DAIS Advocacy Service which covers a vast area
- ◆ Most of the funding is chewed up by travel kilometres and administration costs leaving little for service provision and meeting the needs of people with disability
- ◆ There appears to be no formal training in disability in many service organisation for staff who often have inappropriate attitudes to clients.
- ◆ There is a consistent lack of flexibility in service delivery
- ◆ The distance between and to other resources in rural areas is vast, resulting in much money being spent on taxis or other modes of transport
- ◆ Inequality of fund distribution to and by all services to people with disability
- ◆ There are large waiting lists for everything provided by service organisations
- ◆ Homecare and Respite services do not extend to childcare for mothers with a disability instead they state "they will service the Mother with the disability but not assist with the child's requirements as it not part of their job." Services assume there are families or others to assist, but in many cases the person is alone.
- ◆ Assessment guidelines are too narrow and restricting due to a lack of funds
- ◆ Specialisation in all areas of service lead to duplication and exclusion
- ◆ There is a great need for standardised Assessment processes across Australia
- ◆ Regional areas have greater issues but receive less funding than major city organisation that provide the same service
- ◆ Decision making in services seems to be at a standstill resulting in people with disability constantly being delayed in receiving a service.
- ◆ There are Inappropriate referrals often resulting in people with disability being sent from one place to another.
- ◆ There are enormous restrictions on usage of Homecare hours resulting in one woman with a high level disability receiving 40 minutes per week for essential home chores.
- ◆ Disability services are seen as a 'cash cow' by many including staff, but most of the funds are spent on administration
- ◆ There is no longer personal care available for those over 50 years old in rural areas with the expectation that these people should be in nursing homes.
- ◆ High and complex needs of people with disability are put in the 'too hard basket' and people remain neglected by services
- ◆ There is a total lack of experience in disability by all professions, who come out of their training and are suddenly 'experts' on disability issues that people have lived with

for years

- ◆ There are definite cut-off points in services as in children versus adults.
- ◆ Centralised services means limited access to services
- ◆ The funding guidelines for services often not aligned to rural reality and this is reflected in the lack of services in rural areas
- ◆ The Red tape delays and accountability measures are too detailed and therefore delays processes and restricts services.
- ◆ Money is wasted on simple administration matters such as what type of coffee to buy and who has what car park and impacts on the service delivery
- ◆ Services double up and 'pick and choose' clients resulting in some getting no service whilst others get back to back services.
- ◆ The Equipment waiting lists can be up to 2/3 years in some areas, more in others.
- ◆ There is a total lack of housekeeping resources and services and not enough hours to achieve anything
- ◆ Services and specific requirements are impacting on cost of disability. For instance people are now expected to pay for HACCC services, part of the cost of equipment and this is out of a DSP
- ◆ Attendant care is not transferable across State borders and restricts holidays and choice
- ◆ Hospital to home waiting lists are huge with few options for those who live alone, resulting in Nursing Home accommodation
- ◆ No services except respite if no home based support is available.
- ◆ Need more co-operation between services as one service does it's own thing and another will do the same, but neither communicate. Waste of money!
- ◆ Tailored programmes no longer exist
- ◆ Waiting lists for services in the country are huge and the number of services are small.
- ◆ Service personnel have an attitude that is all their own and they are the so called experts.
- ◆ Supply and range of Equipment and prosthetics available is going backwards.
- ◆ Definitely an urgent need in rural areas as there is an Interpreter shortage in community, hospitals, schools and other vital services, and when Interpreter is needed, who pays?
- ◆ Ageing parents going into hospital leaves people with disability exposed and vulnerable. Example V from a rural town lives with her mother. Mother has recently been in hospital and is ageing also and cannot look after V as she used to. V uses an electric wheelchair and is ventilator dependent at all times. V cannot be without support of some kind at any time. V's mother may have to go to a Nursing Home, leaving V vulnerable and not able to live at home independently as not enough service hours to assist her to do so so may end up in a nursing home with her mother.
- ◆ Captioning services needed across all areas and urgently.
- ◆ Mental Health services are almost non-existent in rural areas and the discrimination and lack of understanding is enormous.
- ◆ Veterans Affairs have different systems for the same issues but seem to be managing somewhat better than those who are not veterans.
- ◆ Government Departments do not communicate with one another, for instance Education Department communicating with Funding Bodies and Centrelink for services to ensure continuity of service.
- ◆ Nursing homes the only option for many people with disabilities .

### Service Provision in the National Disability Strategy.

*Development of standard guidelines and a uniform system and management of Service delivery to people with disability across Australia. Services are ad hoc at best, leaving people with disability vulnerable in the community.*

*Quality Assurance ensures that the service is running as it should business wise, but does not ensure satisfaction from the client base, nor does it ensure that people with disabilities are included in the management of services.*

*Too much money is wasted on administration taking away vital funds for services. Attitudes within services are pervasive and assume they know best with little consultation with individuals.*

*Service organisations rarely employ people with disability, who may at least have more knowledge of disability than some currently do. Employing people with disabilities should be mandatory with funding regimes and would show interested stakeholders that they are serious in the business of providing equitable services and believe in the capacity of people with disabilities.*

### **TAXATION**

Many people raised the issue that there are no tax concessions for people with disabilities who need to purchase essential equipment in order to work. For instance, communication equipment, hearing aids, mobility equipment like wheelchairs which need to be replaced frequently and the repairs of equipment.

Businesses have many tax perks, but those who need essential equipment or vehicles in order to work, do not have any such rebates. Such equipment supports are our eyes, ears, limbs and feet. These pieces of equipment are in the main, the only thing that makes us different from those without disability and are essential to our lives, not luxuries.

### Taxation in the National Disability Strategy.

*Implement a taxation system that includes capacity for claiming a rebate for essential equipment and other relevant disability needs, including vehicles.*

**TRAINING FOR PEOPLE WITH DISABILITY AND PARENTS IN COMPUTERS.** As in the previous issue, training is needed for those who wish to be connected online. A computer and internet modem alone will not facilitate connectivity. What is needed is short term training located in individual communities to enable the appropriate usage of computers and internet.

**Recommend:** That training be offered through a subsidised programme in the community of choice with a short term programme that offers the basic training needed to get started on computer usage and internet exploration. People with disability who are familiar with computers and their usage could undertake this training as a paid position enabling community work experience.

### Training for people with disability and parents in computers in the National Disability Strategy.

*Develop a nation wide strategy to train and update people on computers using existing resources and people with disability as trainers. This will enable the community to be computer literate and meet the isolation of many.*

**TRANSPORT** was a critical issue in all areas. In all towns visited there were no local train services and people with disability have to rely on bus services, taxis and a community transport system which is limited is used mainly by older persons and has a cost also. In some cases the cost seems exorbitant for someone on a Disability Support Pension.

If there is an accessible bus, it is not necessarily connected to other accessible buses or transport services in the area. Taxis are booked permanently during school periods for before and after school transport for children with a disability on a permanent contract basis and are the priority for the taxi company and drivers.

The community transport service is utilised by both people with disability and those who are ageing. In this instance it would appear that the ageing sector get the most benefit from this service which is limited at best.

**Recommend** that Community Transport Services be upgraded and expanded to meet the urgent need in rural communities.

**Recommend** that the DDA Transport Standard be promoted and expanded on by Governments to ensure that accessible buses are rolled out and that journies undertaken do not result in non accessible return journies.

**Recommend** that the Department of Education invest in accessible transport systems for children with disabilities attending school instead of utilising all the taxis (this happens in all areas including major cities) resulting in lack of transport options for those who work, study, train or want to engage in social activities.

Overall, lack of transport options in rural communities and related services impacts on the social inclusion of people with disability and in years to come, the ageing population will require far more options and facilities. The writer believes that to start investing in accessible public transport and infrastructure in rural and remote areas should be a priority for all levels of government.

The DDA Transport Standard appears to fall down in rural and remote areas with few or no accessible coaches linking to major cities and therefore requiring most people with disability to be transported in private vehicles. In instances where people have no family or support persons to do this, the only option is to take taxis to the nearest train stations (limited in the Norther Rivers of NSW as the rail system has been taken away).

### *Tranport inclusion in the National Disability Strategy.*

*Public transport is the right of every citizen, and the transport systems in rural areas continue to blatantly discriminate many of the townspeople. The writer believes that the DDA Transport Standard should be encouraged and implemented in all areas of Australia to enable all citizens to travel accordingly.*

*More work needs to be done by the Human Rights Commission in rural areas on this and other issues.*

## **VARIOUS OTHER ISSUES**

The red tape and expense of being assessed for a drivers license which people without disability do not have to go through. A national licensing system should be just that, not a special system set apart for persons with disability.

A National National Database of Services for all stakeholders, would be a very useful tool for those in the community especially rural areas, to seek out assistance and service.

There is an enormous lack of information on what is available to people with disability

More research needed in disability specific areas with universities being encouraged to expand their Research Departments.

Sue Egan

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