

**Submission to Productivity Commission Inquiry into the impact of Competition  
Policy Reforms on Rural and Regional Australia 1998.**

Please find attached paper prepared by Mr Colin Morris re "**Some Rural & Country Issues impacting on persons with and Affected by Disability**".

As you can see from the inclosed that if Competition policy continues to encourage services to become regionalised, centralised, it will make it even hard for people with disabilities to access help. Often if early intervention is available the person with the disability is more likely to be able to contribute to society. unfortunately people with disabilities do not fit into pigeon hols.

If competition is to be in the health areas and especially for people with disabilities there will need to be **Protocols** set up between fund providers and the purchaser. Tenders will also need to be aware of Rural areas and there requirements.

Evaluation should be on the quality of service to be provided not the cost nor the lowest cost. When tendering is done costing for **advocacy** must be included. Guidelines must be transparent. At present Competition policy doesn't leave room for choice narrowing the criteria means more people fall through the safety net, or cannot access services.

Government must give credit to small agencies, as they are often community based and are effective and efficient providers of services.

Competition Policy and Governments must remember their community service obligations. The community should be involved with the tendering process and unless there is advantages and social benefits to the community the competition tendering should not go ahead, as in England.

As was mentioned at Ballarat I am concerned with the deregulation of newspapers, as to wether it will be another added cost to regional and rural Australians.

Government and policy makers should be supporting Australian enterprises by helping them, not making it harder for them to compete in the uneven playing field of the global economy.

As I mentioned at the Ballarat Consultation to the National Competition review committee, Rural areas have enough problems with the economic down turn without the problems that the National Competition policy is causing to Rural and Regional Australia through tendering, centralising, loss of industry, schools, banks, ect. the areas are being **De-Skilled**.

Yours sincerely



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## **SOME RURAL & COUNTRY ISSUES IMPACTING ON PERSONS WITH AND AFFECTED BY DISABILITY.**

### ***Introduction.***

There are many issues that directly and indirectly affect a person with a disability. These persons can be of any age from the new born, the pre-schooler, the teenager, the young adult to the aged. These persons are particularly in need of assistance that is targeted to seek worthwhile contributions to society to the extent of their ability yet at all times maintaining an integrity and independent spirit that recognises the individual in us all. Such persons in a rural environment find an added weight to bear due to the scarcity if not sparsity of services, particularly for those residing outside large provincial centres. Many of the difficulties are necessarily conceived in the tyranny of distance but not all. Many are developed by policy twists that either ignore the difficulties because the problems are too great to handle or alternatively are simply ignored as being problems impacting only on a diversified, largely disenfranchised, unorganised, politically inopportunitistic number. The random ballot of imposed disability falls across all races, creeds, and criteria whether from birth or acquired later in life due to some unfortunate accident.

Without denigrating from the impact of a disability upon persons with a disability, there is also an at times and, regrettably often so, the forgotten impact of a subsidiary nature that befalls the closer family members and carers of a person with a disability. These family members and carers are people that are more often than not, the forgotten tired people that eventually age with despair and fear as to what will happen when they are either too old to look after the interest and assist their family member with a disability or worry about what will happen when they die.

This outline will simply set out in brief terms some of the difficult issues and aspects that face the rural person with a disability and also that which affects the closer family or carer members of that person. For the purposes of this outline the meaning of disability is confined to a serious physical or intellectual health impairment. The issues raised in this outline are also directed at Victorian experiences but could be applicable in other states.

### ***A. Some General Issues:***

#### ***1. Geographical Isolation and Travel.***

The inability to readily access appropriate disability specific support services be it for health or family support, especially in the early days of the discovery of the disability, and whilst not denigrating the middle years, the greater impact on the aged parents and carers of the elderly disabled person. The nature of the rural environment also means that the full and various connotations of a range of disability must be catered for. The consequence is that specific disabilities, requiring specific attention and displaying particular yet peculiar challenges, are often absorbed without appropriate particular services.

The tyranny of distance and its associated travel and other costs adds a huge expense to an already stretched family budget to access appropriate medical, educational and other services and support. Examples of additional costs include telephone and basic transport.

Case examples abound of families bearing very large taxi bills simply to access basic respite and community residential units that may be otherwise readily accessible in larger provincial centres and the urban environs. To travel up to 150km in a round trip to access at times even a basic service is not uncommon. Indeed many rural school children spend up to four (4) hours a day in transport to and from specialist schools. Even the non disabled amongst us would find this an arduous journey yet many persons with severe physical and other multiple disabilities are expected to grin and bear it.

There is currently a Department of Education (DoE) and Department of Human Services (DHS) proposal for a reduction in rural centre based service centres such as a mooted disallowance for specialist schools to enrol and deliver services to children (under a notional school age applicable to "normal" children) when more often than not these special schools are presently the only barely adequate and already over stretched resource that have the very centre based program that is in demand. *DHS services* to the rural disabled and their family and carers is woefully restricted to one or two hours a month at the residence of the affected person. Its cost efficient but does not deliver anything more than a very basic service and does not allow for carriage of any thing other than small light facilities.

## 2. *Early Intervention and Early Education for pre-school children.*

The need for children with a disability to access centre based programs at the earliest possible stage is vital in the early developmental years. Rural areas lack the disability specific specialists and are also not properly resourced to cater for these or indeed the wide range of needs.

As stated above, proposals are afoot (but yet to be finally determined) to deny children access to early education programs in DoE specialist schools. Some disability specific specialist schools in Melbourne will continue to be resourced by the DoE but not in the rural area. Neither aspect of, certain disability specific schools and then only in the metropolitan area, is acceptable. Yet rural residents will be likely to suffer. The prospect of the DHS providing such a service is rural denial. The DHS currently spends some \$ 3,500.00 per child compared to in excess of \$ 10,000.00 by the DoE.

The current DHS Specialist Children's Services are only accessible for five week block visits after a lengthy waiting period. In addition these services cannot legally offer a necessary centre based program without the parent being present. In many cases the parent should not be present so that the child is one to one with the specialist and not distracted nor looking to the parent for support and guidance. It is not possible even today, to access some of the DHS early education/intervention programs. If you can, and it has no waiting list, then a rural family can expect to travel some 150kms in a round trip to access those that are available. The tragedy is the DoE already has the skilled trained staff and centres in many rural locations that may simply become unusable due to a cost differential in an adequate service delivery. Even at this late stage of 1997 the DoE has yet to announce what its intentions are for 1998.

A potential rural crisis in early education/intervention is in the wings which will severely impact on a rural child's early years of development, to say nothing of the disruption to family life, the partner and siblings.

### 3. *Educational Aspects (Other).*

Rural Specialist Schools are uniquely placed to deliver a whole range of services to their community. They are in many cases the centre of the disability hub and act as a focus and support for the person with a disability and their families and carers. In many instances they are under attack in whom they may take and assist, what they may provide and how it is provided in a cost efficient manner.

These rural specialist schools are today facing the prospect that a DoE financial package (known as the rural size adjustment grant) available to them to assist with the diversity of disability that they must deal with may be removed if not severely curtailed. The very nature of that grant is to allow for the diversity confronting rural specialist schools, yet the expense of meeting the diversity demand is the likely author of its own demise in these times of reductions in funding of Government services. A special vulnerability will be exposed in rural communities and specialist schools if that grant is removed or reduced.

Travel times, early education and adult option aspects and also the need for centre based services and activities mentioned elsewhere in this outline, are also relevant under this heading.

### 4. *CRUs, Respite Care and other Facilities for the young (U.16) and generally.*

Only if over sixteen (16) years of age is a person with a disability able to access CRUs and respite facilities. In the metropolitan and larger provincial areas this difficulty can be accommodated but the rural family is disadvantaged by not having the range of activities and support necessary that assists in overcoming this difficulty. Rural families then have to bear the additional cost of taxis to access these facilities that is not met to the same extent by their metropolitan and provincial city and town fellow sufferers. There are an inadequate number of CRUs and respite facilities for those under sixteen (16) years of age. The strain is again placed on the family and carer with supplementary pressure on family life and the siblings.

Insufficient funding and facilities, or an over crowing or waiting list for appropriate facilities are also evident in rural areas. The ongoing need to access outside funding sources places considerable strain on experienced staff in the undertaking of their trained duties. In addition trained workers in rural areas are also lacking in the staffing of those CRU and respite facilities. Furthermore Community visitors continue to come across locations that appear to abuse the treatment of residents. In some cases the ability of some establishments to spend less than \$ 4.00 a day per person on meals is treated as some form of success benchmark rather than what may be viewed as being adequate or possibly even inadequate nourishment. There are some aspects of these latter matters that are generic to the State and not just rural area.

5. ***Rural Adult Options***

The diversity of disability brings forth the greatest problem for rural adult options. The diversity is not being met.

Realistically, there are very few appropriate adult options available in rural areas inspite of protestations to the contrary by some government employees. Valiant attempts in 1996 & 1997 are being made by DHS via what is known as the Futures for Young Adults program to have appropriate options purchased for the young adult. In some documented cases, none or, no appropriate program or service was available in the rural location of the young adult. If there was, transport, again a very long arduous trip, at the parents expense was required, no travel allowance granted, no travel on DoE buses that went right past the door of the young adult to the location of the program. In 1997 more than one thousand young adults were thrown out of DoE specialist schools into programs that were feted as appropriate for the young adult. Some were clearly successful and others most certainly not. Rural communities appeared to generally cope well with this additional burden.

Employment opportunities are also very limited as are social outings and respite facilities for the person with a disability. These are also necessary to provide relief for the family, siblings and carers from time to time. Many rural communities do superb things for those with disabilities and their families and carers, yet Government assistance in this aspect for rural areas appears decidedly lacking if not inadequate or even at times inappropriate to the rural setting and family.

6. ***Aged Family & Carers & Housing.***

There is a crisis that exists as to the aged parent or carer that presently looks after and cares for their own son or daughter who is also getting old. This aspect is consistent with the general aging of the population. This difficulty is not restricted to the rural community but the difficulty will have a greater impact on rural resources and the urgent need for immediate alternative arrangements. A detailed study of the difficulty and the numbers is necessary so that resources, planning and facilities can be put into place.

Alternative accommodation including congregate, group and other forms of accommodation for those in the disabled community also need to be reviewed. Community residential accommodation is not always appropriate or the best.

7. ***Advocacy Services, Complaints & etc***

There appears to be evidence that the rural disability community lacks access to appropriate and properly trained advocacy services. Some evidence exists that some advocacy services are inadequate in the manner in which they portray the plight of the person with a disability and also their family members. Some advocates simply do not understand the position that they are trying to espouse which causes unnecessary angst to those involved.

An apparent lack of advocacy services is also evident with the consequence that the person with the disability and their family are not readily able to access a qualified person to assist them in their dealing with the many and various departments and organisations that magnetise themselves to the disability community.

There are patently unnecessary constraints imposed on some advocacy and other support organisations services that they are not permitted to disclose policy nor disagree with what Government is doing. This flies in the face of the very nature of the purpose of the service. It also places the rural community in an especially vulnerable position that is not imposed on their metropolitan cousins who may more easily access alternative agencies not so constrained. The lack of availability of Legal Aid to redress these wrongs is again a major difficulty to not only the rural families but others in the same position as the added legal costs is yet again another burden on them that most “normal” families will not be likely to need or deal with.

A trend appears to be developing that those who put forward an alternative and constructive view as to how for example a Government Department should deal with a particular issue will not be listened to, will be excluded from any consultations as to such matters and is just a whinger. Government should seek more rural input into its policies and proposals before they are implemented. The Governments fear of constructive criticism by families about some Government policies is counter productive to good outcomes for the disability community. To exclude rural families representatives from Government deliberations is simply bad. Yet its happening more and more as certain representative organisations make alternative suggestions and constructively criticise and suggest alternatives, they are excluded by the Government policy makers and employees. This is not conducive to good Parent/Government/Disability field partnership relations. Rural families are therefore particularly disadvantaged by this emerging trend of Government.

The appointment of agents, attorneys under power, guardians and administrators for those in the rural disability community needs to be reviewed. There exist anecdotal evidence of an inexperienced administrator attempting to run a farm from the city whilst the client lives on the farm and elsewhere. In addition the manner in which some administrators handle the financial affairs of those in the rural disability community could also be reviewed. Some speciality services need to be considered to deal with particular and peculiar rural issues.

#### 8. *Funding.*

Government policies and funding priorities encroach and continue to deliver inadequate recognition of the disability communities unique difficulties. The rural disability community is capable of being readily ignored by Government and to a certain extent is already being ignored by some existing policies and proposed policies.

## ***B. Recommendations***

1. Some immediate assistance can be provided by resolving the additional cost of transport.
2. In addition the position of the DoE and the DHS as to early education/intervention services must be dealt with now to resolve what is to happen for 1998 at least and then beyond.
3. The DoE has the skills and the facilities but some mixture of services with DoE facilities seems logical to cater for the need for the centre based services.
4. Specialist Schools in the rural community should be and continue to be the focus for disability services.
5. Funding and resource allocation to these schools should be maintained and improved.
6. Rural CRUs and respite facilities and their funding should be immediately reviewed and improved.
7. The extent of the Aged family member and carer and the aged son or daughter still living at home should be ascertained and policies developed to deal with the same.
8. Rural adult options by way of employment opportunities and accessible appropriate programs should be reviewed to ascertain the client, market and marketability of the clients. Whilst this is partially under way with the futures for young adults program it needs further support.
9. The adequacy and skills of rural advocacy services should be reviewed. Consideration for specialised skills as an administrator and also protection of rural clients financial affairs should be reviewed.
10. Alternative housing/accommodation arrangements, also need to be considered.
11. Funding from Government should not be reduced.
12. Consideration should be given to calling for a private market development of alternatives for management, employment and housing options for persons with a disability encompassing also the prospect of formal financial trust management and legal protection facilities.

## ***C. Conclusion.***

The matters raised in this outline are but a brief description of some of the problems facing the rural disability community. By necessity some comments descriptions were scant and some will be open to challenge from others. There is nevertheless a need for families to have information and contact with others and reassurance. Connecting with other families for example with similar difficulties is part of an important process in dealing with a disability. To have a member of your family with a disability is to really know what its like and what is required to deal with the disability. Aside from some of the professionals dealing daily in the disability field, few others are fully aware of the difficulties. These people and families need and are deserving of assistance.

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