## COMMONWEALTH STATE / TERRITORY DISABILITY AGREEMENT (CSTDA) INQUIRY SUBMISSION

## BASIC SUPPORT ESSENTIALS Author - Allan F. Nash

My involvement with people who have disabilities spans around 60 years: I have a 60 year old sister with a profound intellectual disability, throughout 1968 and 1969 I was employed by Grenda's Bus Lines in Dandenong Victoria to transport people whose disabilities ranged from extreme to minor, representing both the physically and intellectually disabled, through this association I gained intimate knowledge of many of the challenges faced by the parents of the children then in 1992 my Grandson Daniel was born with severe intellectual and physical disabilities. For the past 14 years I have attempted to assist my daughter and son-in-law in their quest to insure Daniel is given every opportunity to develop to his full potential.

When reflecting on my experiences with these wonderful people I recall on the positive side many joyous and fun filled moments while on the negative I remain appalled by a common vision that has continued throughout the entire 60 years, that of decent parents and carers in constant search for what can only be described as essential support items such as Mobility aids, Therapy services, Respite etc. These people are often stripped of their dignity as they strive to convince bureaucrats that they are fast reaching the point of absolute despair and would be grateful for "any crumb that can be thrown their way" these are the very people that have devoted their lives to caring for loved ones that can vary in behaviour from an almost vegetative state to overly animated and destructive with each condition presenting extremely abnormal pressures on the whole family, none of these people wanted to be confronted by their individual challenges but each of them has stood tall by accepting their responsibility, these already overloaded people have little energy remaining to pursue these essentials and most often just "make do" which in turn increases the pressure. Currently there are approximately 1.3 million\*\* profound and severely disabled people in Australia, the management of Federal and State allocated funds provided to support people across the full spectrum of disabilities is complex and the current system relies heavily on the discretionary powers of administrators from Government Ministers to agency personnel, I believe the

natural variation in administrators views, and in peoples assertiveness, education, articulation etc. has led to inequitable distribution of the limited funds available which only serves to compound the problem

**\*\*** Source: Australian Bureau of Statistics

There are many identifiable basic support essentials that are generic to all profound and/or severely disabled people, it is my belief that those with the greatest burden should not have to constantly fight to obtain access to these supports but that they should be an automatic right for people who have been categorised as profoundly or severely disabled by an appropriate Government delegated authority I also believe that once established as a right these essentials should be enshrined in legislation to ensure any alterations in the future only occur following responsible debate.

When one notes the generous responses to the various Charity drives that are held each year it is fair to assume that the Australian people at large feel a moral duty to support those among us that have been less fortunate, and would expect the elected "Government Of The Day" to be doing all that is possible to reduce the all to frequent incidences of extreme hardship brought about by 24 hour a day, 7 day per week, 365 days per year struggle of profound and/or severely disabled people and their carers to attain some quality of life in a social environment with ever increasing needs, who through no fault of their own have found themselves in a position where dependence on others is a way of life.

Allan Nash