Submission to the Productivity Commission Inquiry into Long-Term Disability Care and Support

By way of introduction I would ask the Commissioners to read the submission I made to the Inquiry into Better Support for Carers, which will save me going through my life story again and may give the Commissioners some insight into my ideas for improving the lives of those with disability and their families, friends and carers. I have attached a copy or you can access it via: www.aph.gov/house/committee/fchy/carers/subs.htm Submission 830 and supplementary.

I am very pleased to be able to again give my opinions on how I believe the system should be changed to improve long-term care and support services for people with disability and their carers and families, and thank the Commission for the opportunity to do so.

Before I address some of the questions in your Issues Paper, I would ask that you consider that I am not an economist or an actuary or a legally qualified person. Nor am I an expert in the provision of government services or a member of the academia. Many of the questions you have posed require expertise which is way beyond my knowledge.

But, I am an expert in the care of my daughter and in understanding her needs, both physical and emotional, and in my own needs as a carer. During the past twenty years I have been involved with carer support groups, government advisory committees, NGO management committees and informal support for other families with children who have a disability. I have tried to keep up to date with available services and assistance and to disseminate that information to others. I have also been active in lobbying for more and better services and better standards within those services.

As a family we have lived in a small coastal town, an even smaller rural village, the western suburbs of Sydney and now a major regional centre of NSW, so we have experienced service provision (or the lack of it) in a variety of settings.

Hopefully this experience means that my input will be of value to the Commission.

WHO SHOULD BE ELIGIBLE?

The Terms of Reference for this enquiry asks the inquiry to assess a Long-term Care and Support Scheme for people with a **severe or profound disability**. Too many people are already excluded from receiving services due to the lack of funding and poor or inefficient allocation of that funding. Eligibility should cover as many types and levels of disability as are humanly possible.

Obviously those with a severe or profound or multiple disabilities should be given priority, but, by excluding those with moderate or mild disabilities, you create the situation where someone with a mild or moderate disability is not able to reach their full potential and instead of being able to contribute to the community and/or workforce in the future, becomes another statistic in the unemployment or disability figures. Investing in therapy and equipment as early as possible will always create a better financial outcome for the government.

The Department of Veterans Affairs has a system in place for TPI pensioners, where those with the highest needs receive a Gold Card which covers all services other than permanent accommodation, and those with lesser needs receive Orange or White Cards. There is an assessment process and allocation of benefit system in place which means that holders of these cards may use them for whatever services they are entitled and may use whichever provider they choose, as long as that provider is registered with the DVA.

Recently a family member, who holds a TPI Gold Card, had a severe stroke. Within weeks he had every therapy he needed, every piece of equipment he required and home modifications done before he left hospital. As his recovery progressed he was able to organise therapy appointments with his chosen therapists at times which suited him. At each stage of his recovery he has been able to access whatever he has needed because he has been assessed as entitled to these services. His recovery has been remarkable and this can only be attributed to being given the services and equipment he needed when he needed them. Instead of being totally disabled and requiring nursing home care, he is able to continue living in his own home with very little support. This is a positive example of how things can work.

This is a far cry from the situation which faces most people who are born with or acquire a disability through no fault of their own. The Commissioners already know how drastic the situation is for people with disabilities so I will not repeat the many problems faced on a day to day basis.

I would ask that the Commissioners look into the structure of the TPI system and see whether its modelling could be adapted to suit a new disability scheme e.g. Gold cards for those with lifelong, severe disabilities, orange for those with conditions which may improve or deteriorate and would need to be reassessed, and white for those with conditions which will only last for a short period of time.

These cards would be accepted Australia wide and therefore people with disabilities would not need to be reassessed if they chose to move to a different state.

Permanent accommodation options would not be covered by this system, but I will outline my thoughts on that later in this submission.

Identification of a disability usually begins with a medical diagnosis or educational assessment. Once that identification is made, the person should be assessed using a Functional Ability Test, which would verify their level of ability and need for assistance. At present an IQ test is often used, but many people with average or high IQ can have functional disabilities e.g. autism, cerebral palsy. The family/living situation should also be taken into account as part of any assessment: some families cope better than others, some have other responsibilities e.g. other children, some carers have health problems of their own.

A crisis is looming for aging carers, and I believe that this is the group most in need of additional support and help. Something must be done to provide permanent accommodation options for the adult children of these carers, or to support the carers so that the person with a disability is able to remain in their own home if they choose.

Early intervention is also a critical area. If supports and services are provided as soon as a need is identified, outcomes for the person with a disability are greatly improved and stresses are removed from carers. Waiting for months or sometimes years for a therapy or a piece of equipment only exacerbates a very difficult situation and often results in health problems for the person with a disability and unnecessary stress for the carer.

I believe that every person must be treated individually**.** Fairness is a difficult concept when dealing with different levels of disability, different personalities, different family situations and different geographic locations.

Fairness is not everyone receiving the same: fairness is everyone receiving what they need.

WHO GETS THE POWER?

Individuals, individuals, individuals. People with disabilities and those who care for them are in the best position to know what they need, and are more likely to be able to find the best solutions and most cost effective way of providing those solutions.

At present we are given few options. We must use the service providers which have been funded by the government whether they are able to provide the service we need or not. We are expected to accept whatever a service provider is prepared to offer, and we are supposed to be grateful for it. Individuals need to be able to decide what they need, and how that need will be met. Individuals must be able to choose who provides a service and how and when that service is provided.

The only way to have this positive outcome is to have individualised funding. While service providers will say that this creates uncertainty for them, if they are prepared to provide the services which are needed, at the standard which is required they should have nothing to fear. This is how the real world works. The power must be removed from the bureaucrats and service providers and returned to the people who know what best suits their individual needs.

People with disabilities and their carers have always been subject to the power of others, and that situation will not change until they are recognised as being able to make their own decisions. Yes, there are some who will find difficulty in doing that, but if the system is set up so that they are given the information and assistance to make those decisions, I believe there will be much better outcomes.

The amount of financial support and service entitlements each person receives will always be decided by someone else. We are asking for assistance from the public purse, and accountability is necessary.

The assessments outlined above would create a tiered system of financial and service entitlement. Those with the highest needs receive more, those with lesser needs receive less, but **always what they need**.

There are many assessment tools already in use. As my most recent experience of assessment when my daughter was transitioning from school to post school shows, sometimes they do not work. (see attached submission to Inquiry into Better Support for Carers) How could an assessment be made that a person who is totally dependant, cannot walk, talk, or feed herself is able to 'Transition to Work'? And why didn't commonsense prevail when this blatant error was questioned?

An appeals process must be incorporated into any assessment tool and this appeals process must put the onus onto the assessor to prove their outcome rather than the appellant needing to again prove their need. An Appeal Board with independent members would be required.

WHAT SERVICES ARE NEEDED AND HOW SHOULD THEY BE DELIVERED?

I believe that you, the Commissioners, already know what is needed. All services need to be increased and that takes increased funding as well as innovative thinking. Other submissions to this enquiry and presentations at the public hearings have given specific as well as general ideas on what must be done.

I also believe that the best way for services to increase, be delivered and improved is for individuals to have the choice of where they spend their funding. If there is a need, people with disabilities and their families, friends and carers will innovate so that need is met. New service providers will come into the industry if there is a shown need, or existing service providers will improve the services they provide and be more flexible in that service provision if they are not guaranteed block funding.

By providing timely and flexible services, no encouragement to participate in the community and workforce will be required. With the right services people with disabilities and their carers will be empowered and will be able to contribute.

They will also be the driving force in keeping the good aspects of current approaches in place. Demand will keep the good and weed out the bad. That is the real world.

In rural and remote areas there will obviously be less choice for those needing services, but this is where real innovation will take place. If people with disabilities have the power to create solutions, they will. Necessity is the mother of invention. The system just needs to be flexible enough to allow that invention and innovation to happen. For those services which cannot be supplied locally some form of transport subsidy, similar to IPTAAS, could be included in the funding entitlement.

The original and any supplementary assessment would be accepted by all States and Territories, and by all service providers as they are not allocating the funding. The individual has the funding to pay for the service if they choose. This would eliminate the many, many forms required under the current system.

FUNDING

My thoughts on funding revolve around two coinciding models.

The first would cover the cost of therapies, equipment, respite services, continence aids, home care, etc by way of a National Disability Insurance Scheme, funded by an increase in the Medicare levy. This model has been discussed for some time now and I'm sure there are many people who are much more able to elaborate on that than I. This would be the funding allocated to individuals on a regular and ongoing needs basis, with the individual having the power to choose the way in which it is spent.

While many people will be against an increase to the Medicare levy the people of Australia must realise that people with disabilities and their carers cannot continue to shoulder the burden alone. I believe that the majority of Australians will understand this need if it is explained properly.

The second would be a future fund, and it will need to be a very large future fund, to cover the cost of permanent accommodation placements. Carers need to know that the ones they love are happy and well cared for so that they can enjoy the rest of their lives. More and innovative permanent care placements are desperately needed and there is no solution to this other than increased funding.

This fund would need to pay for the capital and recurrent staffing costs for permanent accommodation for those who need it. This fund should be able to earn enough income to maintain current needs and increase the number of permanent places each and every year. Again, I do not have the expertise to put actual figures on this, but I know that there are a huge number of aging carers who believe they will die not knowing what will happen to the person they care for.

ORGANISING AND IMPLEMENTING A NEW DISABILITY POLICY

The fact that there are so many different governments involved in providing and funding current disability services is a major part of the problem. Every government has different priorities and programs and that creates difficulties for the service users.

I believe we need a new broom through the system. The amounts given to the States for disability services at present should be retained by the Federal Government, and each State should be required to contribute on a pro rata basis to the Federal fund. The funding and management of all disability services should be federally controlled with the States receiving a fee for service provision if and when it is supplied, as would happen with all other service providers.

Existing arrangements with NGO's could be continued, but yet again on a fee for service basis. When a person with a disability chooses to use that service, because it suits their needs, then that service would be paid for providing that service. Block funding creates organisations which are often more interested in their corporate structure with many levels of management eating away at funding which should be directed to service provision. Smaller, locally managed organisations which have direct contact with service users should be encouraged.

Whatever scenario eventuates after this inquiry, more workers are going to be required. The number of people with a disability who require services is growing and we need to make this industry more appealing.

The rate of pay needs to be increased for disability support workers. At present a person working on a supermarket checkout receives more per hour than the person I trust to care for my daughter at her day program!

There is also a dire lack of therapists. Assistance with or waiving of HECS or scholarships could help to encourage people to qualify in these fields. These incentives could also be used to encourage allied health professionals to practice in rural or regional areas.

Unfortunately, any new scheme will take much too long to implement for many people with disabilities and their carers. I understand that transitioning to a new system will take time, but would hope that the next Australian Government will make disability service provision a priority. Disability issues need to be taken seriously and I hope that the when the recommendations of this inquiry are tabled, those recommendations are acted upon by the government and accepted on a bi-partisan basis.

An NDIS in the next term of the parliament, empowering people with disabilities with the right to individualised, self directed funding would be my hope. While this may be an unrealistic hope, I believe it is not impossible to at least have the structure and organisation of an NDIS finalised within the nextt 18 months and implementation should be possible not to long after that.

Disability can happen to anyone at any time. Our politicians need to realise this, and be brave enough to really do something to allow people with disabilities and those who care for them to reach their full potential.

Yours sincerely

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