Submission to the Productivity Commission Inquiry
into
Disability Care and Support

For the past fifteen years I have been dealing with health and disability issues. This involvement began with the birth of our first child and the subsequent knowledge that she was affected by a degenerative neurological condition, which ultimately took her precious life three years ago. The twelve years of 24 hour a day care that she required compelled me to ensure that we did what ever we could to make her happy and comfortable and to keep her as well as could be expected under the circumstances.
The full time care of a profoundly disabled child who can't vocalize, move without assistance and who can't feed or toilet herself certainly makes demands on ones lifestyle. It also brings opportunities to witness and experience the systems that exist to provide support for families caring for someone with a disability. I have seen the good, the bad and the ugly. I have seen what works and what doesn't work. I have contributed in a variety of ways to improve the experiences of others dealing with health and disability issues and that is why I would like to contribute to the enquiry into a national disability scheme.

I am presently the national president of the Australian Leukodystrophy Support Group. This is a voluntary role as has been the case with all of the committee involvements I have had over the years. This gives me a good insight into the national perspective of disability support and helps to identify shortcomings in the present systems.

What I have learnt is that disability support should be based on the needs of the individual and their family not on the name of the condition if there is a diagnosis or cause of the disability.
The incidence or recognized profile of a disability should not entitle those with that condition to additional or favored supports.
Supports should be implemented at the most appropriate time to improve outcomes and reduce known complications.
Waiting lists for services, procedures, aids and equipment and any other intervention must be done away with.
Service provision needs to be provided in such a way that the individuals with disability are the focus of the support and not the viability of the service provision agency.
Unnecessary duplication and bureaucracy needs to be minimized to ensure that support is obtained efficiently.

The TAC in Victoria should be used as model or template to finance a disability scheme. It is unethical in the present scheme of things to know that someone who is injured as a result of a road accident has more care and support that anyone else in the community who has a disability. Even a proposed Medicare levy to pay for a disability scheme would be desirable and equitable. The most important aspect of this exercise is to agree to create a scheme that is essential for our society to care appropriately for those who for what ever reason have special needs. A new system needs to be implemented that will resolve so many of the issues that are not being addressed by the present mish mash of uncoordinated and unaccountable supports.

As the parent of a profoundly disabled child with high medical needs you needed to take on additional roles to have the disability system work for you. You become the primary carer, where you often have to sacrifice job or career to devote the necessary time and energy to care for your loved one. You are never compensated for this financial sacrifice and you will never make up for it. For ten years I survived on the support of the Carer Payment but during that time I was not able to contribute to a superannuation scheme so I know I will not be able to fund my retirement. You also need to become an advocate for your child to access the supports that you are entitled to. This is because present supports are more likely to be reactionary rather than proactive. You need to be resourceful to find your way through the disability maze, you go to get support it doesn’t come to you.

The role of the paid carer needs to be addressed so as to provide quality, reliable care to those with a disability and to ensure that the primary carer is also supported. Paid carers must be rewarded appropriately for the responsibility and complexity of the care they provide. Support to disabled people should not be refused because a service provider won’t allow their workers to provide the care that the client needs. There needs to be quality training for all paid carers to carry out their work safely and these skills need to be reviewed regularly.

I felt that we were able to provide very good supported care for our daughter. This mainly came about because we qualified for what I call the Rolls Royce of support, The Family Choice program presented by the Royal Children’s Hospital (RCH), Melbourne. This program provides excellent, well resourced, quality care and support but it is restricted to a limited number of families of children with very high medical needs. Such a program should be the bench mark for a disability system that is created under a national disability scheme.
Similarly we accessed an amazing early intervention and school program when we enrolled in our local Special Developmental School funded and resourced by the Victorian Education Department. It was like a breath of fresh air to see my daughter’s school working so effectively to provide very positive experiences and outcomes for disabled children and their families. Another valuable support that we could access was Very Special Kids a respite facility and hospice for families of children with life threatening conditions. It is a sad indictment there is only one such facility like this in Victoria and it is an equally sad indictment that we have young people in aged care nursing homes instead of more appropriate supported residential accommodation.

There are major inequalities in disability service provision across the nation. Each state and territory has taken some responsibility for assisting those with a disability in a very ad hoc manner and federal support hasn’t been able to correct these inequalities. I know that I would rather be dealing with a disability in Victoria than elsewhere in the country. This dilemma needs to be rectified so that the needs of all those with a disability are appropriately supported everywhere in our nation. The gaps and inadequacies in the system for disability support are a major reason why there are organisations like the

Australian Leukodystrophy Support Group. A significant amount of the assistance we provide is to top up and fill the gaps that are not being provided by the present system. We recently obtained a grant to employ a Family Advocate to assist our families to work through the system to obtain basic supports that they desperately need. This highlights the fact that the present system is difficult to navigate and access. Our viability as a disability support group is always on the edge with no government funding to assist us even though a lot of our time and energy is spent seeking funding and grants to assist our families.

I hope a national disability scheme is implemented sooner rather than later. Someone needs to be socially responsible enough to stop the waste and inefficiencies of the present arrangements and start afresh on a clean slate with an even playing ground. All this with the primary focus being much better care and support for those with a disability and their carers.

My background in health and disability is as follows:

Past Parent / Consumer representative on the RCH Community Advisory Committee.
Past Consumer Representative on the RCH Board Quality Committee.
Past Consumer Representative on the RCH Clinical Quality and Safety Committee.
Honorary Life Governor of the RCH
Nine years as school council member and Vice President of the Croydon Special Developmental School Council.
Past committee member of the Genetic Support Network of Victoria (GSNV)
Present national president of the Australian Leukodystrophy Support Group (ALDS)

Thank you for the opportunity to present my personal submission for the establishment of a national disability scheme.

Peter Phillips