

---

**Submission To The Productivity Commission Inquiry Into A Long-Term Disability Care  
And Support Scheme from Anne Murphy**

---

Like many others, I welcome this long overdue inquiry into long-term care and support for people with disabilities. My hope is that this inquiry will lead to a systemic change in the way people with disabilities are supported and cared for in Australia.

I am the mother of a seven year-old son with Angelman syndrome, a condition that is characterized by global development delays and intellectual impairment. He has no speech but communicates through gestures and signs. He can walk independently but has some balance and co-ordination issues. He suffers from epilepsy. He requires assistance with daily tasks such as toileting, dressing, washing etc. He has frequent sleep disturbances and needs to be settled back to sleep (by myself or my husband) a number of times most nights. He is very curious and needs constant supervision. He continues to progress and build up new skills but he will never achieve independent living. He is a happy and delightful child who lights up our lives with his beautiful cheeky smile and infectious laughter. Despite all the challenges we face in looking after him, our world would not be complete without having him as part of it.

My family's story of dealing with the issue of discovering your child has a life-long disability and trying to access services to support his and our family's needs is very similar to many others:

- We have painstakingly filled out a plethora of near identical forms that each specialist, government department and service provider has required.
- We have been on (often long) waiting lists for early intervention, equipment and respite.
- We have been overwhelmed with trying to access information on what services we can access for our son, including basic information such as different schooling options.
- We were offered no counseling or advice when we given our sons diagnosis over the phone. We were expected to just deal with it ourselves and have mostly had to wade our way through the system on our own.
- We have discovered that our son, and children with disabilities in general, do not enjoy the same rights and opportunities at school or in the community as their "typical" peers.
- I have had to give up work in order to juggle the differing needs of my two children, deal with the exhaustion of sleepless nights and due to the lack of adequate before and after school care for children with disabilities.
- We worry about what will happen to our son when we can no longer look after him or if we die. We can set up a trust to provide for him financially but there are no firm options out there for using the money that is saved, such as supported accommodation in a village setting.
- We hope our other son can lead his own life and will not have to look after his brother when we no longer can.

Despite all of this we consider ourselves lucky.

- Our son continues to progress and does not have high medical needs or equipment and support needs such as wheelchairs, accessible transport and accessible housing, that so many struggle to access or pay for.

- We have the knowledge, education and ability to advocate and fight for our children's rights when and if needed.
- We have somehow managed to cope, deal with some very dark periods, overcome hard times and have been able to stay together and grow stronger as a family.

Unfortunately throughout the journey with our son we have met, seen and heard of too many people and families who have not been so lucky. They have suffered financial hardship, severe mental illness (including attempted suicide), marriage breakdown and other hardships that can be directly related to a lack of basic support when they needed it. We continue to see how completely dysfunctional, unfair, and inadequate the system is and it scares us as we know that we face many more unknown challenges in the future as our son and we grow older. We wonder how we will continue to cope. All we want is to know that a system exists that will provide him with the care and support he needs as his and our needs change. We need to be able to plan our lives and his so that we can support him to reach his full potential and be a valued member of his community.

I believe that restructuring the current system so that it is no longer crisis driven but instead is aimed at providing long term care and support will make an enormous difference to the lives of millions of Australians affected by disability.

I have contributed to and support the ideas and visions for a new scheme that have been proposed in other submissions to this inquiry, including the submission from the Genetic Support Network of Victoria and Australians Mad as Hell. Rather than repeat those ideas here I will briefly summarise some of the key ideas that I feel should be part of a new scheme and some that affect my son and my family personally:

**Eligibility:** All people with a disability that prevents them from fully and effectively participating in all aspects of life, on an equal basis with others, and who require additional assistance, care or support to do so should have a **legislated** right to assistance. This includes people with "mild" disabilities such as learning disabilities where support and therapy should be provided at school. Families and carers should also be entitled to support in their caring roles.

**Structure of a new scheme:** A new scheme should be a Nationally structured scheme where the cost is borne by the whole community through a tax or levy, similar to the medicare levy for health care support. It should be based on a single, secure, national database that:

- Allows for seamless integration across government departments, service providers and health professionals for accessing information and judging eligibility for services and will reduce time-consuming and repetitive paperwork.
- Will provide searchable information on local and national services
- Will enable users to provide feedback, updates and other information that can be used to inform or for research purposes in order to further develop and refine the system.
- Will ensure that wherever a person lives in Australia they will have access to the database to manage their funding or for information and updates.

Everyone who is eligible for support should have a care-plan that looks at short, medium and long-term needs so that people with disabilities or their families/carers can plan their lives and their futures with reassurance that their support needs will be met.

The new scheme should be an integral part of the national disability strategy with the aim of breaking down the disabling barriers that people with disabilities face in their everyday lives and promoting the principal of social inclusion. Providing support will allow people to participate more in their communities and allow them to live as “ordinary” a life as possible

Most importantly a new scheme should be just that “A New Scheme” and not an attempt to add on to, or patch up the current completely dysfunctional system.

**Individualised and Self Directed Funding:** People living with a disability or their family/carer should always have the power to make choices and decisions that affect their own lives. Everyone has their own unique set of needs and because of this individualized (short-medium and long-terms) care-plans should be developed with in-put from the person with a disability or their family/carer so that they can decide on the most effective use of funds. They should then have the power to take responsibility for that funding and purchase equipment and services themselves if they wish. The system should also allow for training or a case-manager to be assigned if people are unable or not willing to manage their own funds.

This shift to individualized funding should be a central part of any new system. Both in Australia and overseas, individualized funding has been shown to work well and have positive benefits for people with disabilities and their families/carers. They become consumers, clients and even employers. It is a more efficient use of funds as it cuts out the middle-man’s administrative costs and will also drive an industry that delivers good quality and competitive goods and services.

I would also like to recommend that there be an immediate move towards providing more people with disabilities and their families with individualized funding packages **now**. This will catalyze a shift in how services are provided and allow service providers to gradually adapt their systems to a new consumer driven model.

#### **Services that should be funded through a new scheme:**

- Early Intervention Services
- Therapies/treatments
- Personal Assistance
- Respite Services
- Education support
- Workplace Support
- Aids and Equipment (including vehicle and home modification)
- Supported accommodation

This is just an overview of the services required. Within each of these there should be flexibility and options so that people with disabilities and/or their families have choices. For example supported accommodation could include support to live independently but should also include

options to live in shared accommodation arrangements or in village settings within the broader community.

For many of these services the infrastructure still needs to be developed (e.g. supported accommodation) and/or there is a real need for more training of people to work in these areas. This means that in addition to providing services we need to start investing in building infrastructure and training more disability support workers/therapists/specialists now to cope with demand and to be able to offer adequately supported services. This also means that therapists and disability workers need to be paid competitive salaries in order to attract and retain them in the disability support sector. This will ensure the industry has quality workers who will have better job satisfaction, and retention of workers within the industry will rise considerably.

**Raising Awareness of the need for a New Disability support System:** A well-designed awareness campaign to educate all Australians on why we **all** need to fund a new scheme will be essential and should be initiated immediately. All Australians need to be made aware that disability can affect anyone at any time and that they already pay billions of dollars in taxes and donations for an inefficient system that does not work. A reformed system will benefit everyone and will be much more cost-effective way of spending out taxes.

In summary, I believe that a well-designed and cost-efficient tax-payer funded system will be sustainable and will benefit all Australians with disabilities who need support.