

From:
To: [Community Affairs Committee \(SEN\)](#);
Subject: Spam: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 17 January 2013 10:08:38 AM

Please consider this email a formal submission by me to the Senate Standing Committee on Community Affairs Inquiry into the National Disability Insurance Scheme Bill 2012.

The current disability system has many problems that need to be addressed.

I am the current Chair of the Guillain-Barre Syndrome Association of NSW Inc, a health, charity, support group for those impacted by rare acquired peripheral neuropathies such as GBS and CIDP (Chronic Inflammatory Demyelinating Polyneuropathy). An acute GBS attack could see an otherwise healthy individual struck down within 24 hours, in ICU on life support and only communicating with eye blinks. They could remain in ICU for months and then spend many months or years in rehab and then they may not full recover suffering from residual effects such as difficulty walking, using their hands and suffering significant pain. many require ongoing treatment such as IVIG/medications to maintain a semblance of lifestyle and walking aids and assistance with basic needs such as getting dressed, bathing etc. There is no cure and we do not know why this occurs to some with any certainty. All too often I hear from sufferers, especially younger adults who are placed in aged care facilities, due to a lack of age appropriate care facilities, until they recover sufficiently to go home. I know much of the journey to recovery or GBS/CIDP sufferers is the mental aspect and the knowledge most will eventually recover but it can take a long time. Putting a young adult just starting their life in aged care with people approaching the end of their life can be seriously detrimental to their recovery both mental and physical. If you are 80 or 90 years old you accept your friends will pass away but not if you are 20 or 30. I believe we need more focus on age appropriate high care facilities for 18-55 year olds.

The main features of the NDIS that will make a difference to the community are:

More employment of people with disability and less reliance on social welfare,
People with a disability can plan their lives and pursue their goals and dreams,
Increased ability to coordinate services to suit the "whole" person/family

The most important services for the NDIS to provide are:

Employment support, Support for families and carers, Flexible in-home/outside home respite

I support the introduction of the NDIS.

For too long an army of unpaid/low paid carers have shouldered the burden of caring for those living with disability, often to their own personal detriment. Many carers have had to leave work to care for a disabled loved one, not only losing income but their skills are lost to the nation. Further, there are many people living with disability who want to and could work with just a little more assistance such as cooking, bathing, dressing, and transport to work etc. Earning a wage will empower these fellow Australians to more fully participate in our great way of life. We know those living with disability are over represented when it comes to obesity, alcoholism, asthma and other health conditions associated with a sedentary way of life. As such, whilst the NDIS might appear expensive there will be many who will be able to for the first time, work and pay taxes, socialise,

mobilise and have goals and aspirations just like able bodied Australians. In former times many disabled were placed in care facilities shut away from the general public and then in more enlightened times many of these facilities were closed and it was decided these people would be better off in the community. But in reality instead of shutting them away in a facility they were instead shut away in public housing, still with no hope of participating in mainstream society. Then currently we often place young disabled persons in aged care facilities, wholly inappropriate for their recovery. The NDIS is another stage in our enlightenment of how we perceive disability. Getting an effective scheme up and running will present huge challenges and it won't be cheap. However, for the hundreds of thousands of Australians living with a disability, their carers, family and friends the NDIS presents an opportunity for an improved quality of life. If you have a permanent or long term disability or chronic illness that has no current cure and improvement in the quality of your life is like another Christmas. This is why I support and advocate the need for the NDIS.

I agree for my submission to be made public

Regards,

Mr Mark Kunach