From:
To: Community Affairs, Committee (SEN);
Subject: Spam: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 24 January 2013 11:01:18 PM

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.

The current system does not work in our family circumstances where our daughter's illness has resulted in a disabling condition. The problem is due to widespread misunderstanding about the nature of the illness and its effects, as a result it is not recognised as a disability. We are unsure of the reasons why: it may be due to the conservatism or limited understanding among Australian medical practitioners, or perhaps government wants to avoid the costs associated with recognizing yet another chronic and debilitating illness that can shatter the lives of sufferers and the lives of family members.

The illness I am writing about is chronic fatigue syndrome (CFS). Like many young people with CFS, our daughter showed the first signs of the condition when she was in the later part of her final primary year, she was aged 11. Until that time she had been a robust, sociable, energetic and high-achieving child. For example, in the months prior to becoming ill she performed (for the second time) in a local dramatic production, she won the prestigious Voice of Youth competition for public speaking, and she received distinctions in her ballet exams. Since becoming ill her world has gradually receded around her. She is unable to attend a conventional school, her social world has largely disappeared, and the activities and things she once loved to do she can do no longer. Now, for much of her time, she is bed-ridden and exhausted, she is often very nauseated, and frequently feels dizzy, confused, depressed, along with other symptoms of the condition.

Not only has CFS taken a dreadful toll on our daughter, it has severely affected our entire family, in particular her mother who has suffered physically, emotionally and financially as a result of caring for a sick teenager for the last two and a half years. While it has been traumatic to witness the effect of CFS on our daughter, it has also been traumatic to experience the attitudes and ignorance of others. While it is easier to understand this in the general public (friends, family and other parents) it is especially disappointing to find it among medical professionals. Not only has our experience of GPs been one of denial or disbelief, it has been suggested (more than once) that we (her parents, but especially her mother) are somehow to blame and that we want or need her to be sick. As well as being offensive, nothing could be further from the truth.

Generally, we feel that the health care and human services systems have failed us. We have gone from one medical specialist to another, most have no idea about the illness, or adopt antiquated approaches to the disease, believing that it is treatable (solely) with methods such as graded exercise or cognitive behavioural therapy. The latest research suggests that CFS is either an auto-immune illness (like Crones Disease or multiple schlerosis) or the result of compromised genetic function. As such, the illness is – as the name describes – a syndrome. Medical science is still struggling to understand CFS and, at present, it is not curable, rather, it requires ongoing careful management so that most sufferers are able to live within their limitations.

For these reasons the whole system does not work for our family. The medical profession does not understand CFS and is unable to assist us (for example, despite repeated requests, our usual GP has refused to give us a referral to a paediatrician, although she has to several other specialists, none of whom helped); my wife gets no financial, respite or other assistance, despite her loss of income and the near full-time caring our daughter requires. For these reasons we have been both disappointed by the current arrangements, but fear for our daughter's future.

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

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, Older parents and families will not worry what happens when they can no longer provide support

The most important services for the NDIS to provide are:

Life-skills, Support for families and carers, Case management, planning and coordination

I support the introduction of the NDIS.

The right to a decent standard of health care and to participate freely in the civil, political, social, cultural and economic domains of life are fundamental human rights. These are rights that should be available to everybody, having a disability should not be a barrier to participation if this is a person's choice.

Up until now certain restrictions, such as those caused by illness or disability, have prevented the achievement of these rights. The NDIS will help remove many of these barriers so that people can enjoy the rights to which they are entitled. It will also help alleviate the responsibilities – and stresses – that lie heavily with carers, as well as their apprehensions about the future. In addition, by giving citizens greater independence and capacity for participation, along with improved quality of life, this will help them to contribute and enrich the communities in which they live.

I agree for my submission to be made public

Regards,

Mr Conrad Gershevitch