

From:
To: [Community Affairs Committee \(SEN\)](#)
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 24 January 2013 8:10:00 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.

I have Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. I have suffered from it for 17 years. I am also a PhD researcher into the condition.

The major issues that I have had with respect to assistance during this condition has been as follows:

- * No access to ongoing treatment such as physiotherapy and chiropractic.
- * No in home assistance with domestic issues
- * Limited access to medical assistance
- * Limited access to medical investigations (particularly non-mainstream)
- * Limited access to non-PBS medications

When doing research on the issue of ME/CFS and interactions with social institutions, the participants indicated that:

- * They had no knowledge of organisations that could assist or those organisations that did exist would not assist them
- * They needed in home care with domestic chores and shopping
- * They needed an advocate to deal with issues such as mistreatment by medical staff, problems with Centrelink, discrimination, legal problems (eg accessing income protection, total and permanent disability, etc), employment issues, etc
- * They required someone to assist with coordinating treatment plan and organisation of appointments
- * They needed transport assistance
- * They needed assistance for the spouse and children to help them cope with their condition and the impact upon the family unit
- * They required access to allied health services
- * They required access to non-PBD medications
- * they required access to alternative health supplements

The primary reason for these needs was as follows:

- * lack of income to fund access to medical assistance, supplements, allied health, domestic assistance and medications
- * absence of advocate services that are prepared to assist with ME/CFS (in part because they do not understand the condition and in part because the person cannot fund their involvement)
- * Inability to organise things for themselves.

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

Ensure support and equipment is available when needed, People with a disability can choose the types of support to use, Better access to mainstream support and

services, Better access to education and work opportunities, More rights for people with a disability, People with a disability can plan their lives and pursue their goals and dreams, People with disability can choose who comes into their home, Minimising the number of times people have to tell their story in order to get support, Access to reliable information about support options, People with disability/family will influence the types of support and services offered

The most important services for the NDIS to provide are:

Therapy and allied health services, Education support (technology/services/equipment), Support for families and carers, In-home care and domestic assistance, Flexible in-home/outside home respite

I support the introduction of the NDIS.

I support the NDIS because I have been in the position of those who have a disability. despite the fact that I have had access to insurance. The insurers simply denied the existence of ME/CFS or that I had it. For that reason I was left out in the cold and I had no access to anyone to help me with my needs, little money to fund access to medical personnel (and they all charge) and no means to fund allied health and supplements. What was the most disempowering aspect was the inability to get a law firm to represent my interests. In the end I had to take the matter into my own hands when I was well enough to do so. I succeeded in getting funds, but not before the insurers had forced settlement through financial duress.

Once I succeeded I had access to medical assistance and investigations. Everything that the NDIS provides, I was able to finally obtain from the insurer. The insurer's actions caused me to deteriorate. Obtaining assistance with all that I required enabled me to participate in a PhD and to get back into employment. I had increased quality of life. When they took it away again, I declined.

Those with ME/CFS, like all people with a disability, deserve access to the best possible opportunity to improve their health and quality of life. Their families deserve to obtain assistance and have a break from the pressure and day to day grind of their partner's illness

I agree for my submission to be made public

Regards,

Mr. Geoffrey Hallmann