

From:
To: [Community Affairs Committee \(SEN\)](#)
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Friday, 28 December 2012 8:14:57 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.

My age is 63. I was diagnosed with MS in 1989. I have the Home first from DHS but there are not enough hours for my needs. I am severely disabled.

As the primary care giver, my wife shoulders the bulk of this. She is reaching breaking point. The DHS recognised this. Extra care has been approved by them since 2009 but never granted due to funding restrictions.

I am living at home and wish to continue. However, this is becoming more and more impossible. Being committed to some facility appears to be the only answer. Neither of us want this. And it is more expensive for the management of my condition.

Read the following which describes where I am at at the moment:

Changing tracks - for Kevin

August 10, 2012 , 6:24 PM by Rafael Epstein

Changing Tracks - The song that was playing when your life changed tracks, maybe the song that made you realise why you made your decisions, or simply the song that means the most to you.

Email me at

This week's Changing track was from Kevin;

In 1973 I opened the door to this beautiful girl.

By 1974 I was married and the next year we had our first daughter and a couple of years later, the second.

Life was good and it could not have been much better. I was in the middle of very interesting work, she was happily living at home and we were content in the country to which we had moved to spend the rest of our lives.

All this changed in 1989.

I was diagnosed with MS and from there until now I have lost many things.

Rather than list them all I could perhaps illustrate this with the description of my

desire to go for a meal out. Not a big ask, you would think. But think again.

I was too embarrassed to go because I thought I would make a disgrace of myself. (Problems of the bladder and bowel).

I should not have worried because before that I would have choked on the food long before. (Swallowing problems).

Not a problem. Well before that the waiters couldn't have understood me. (Speaking difficulties and neuralgia meant speech could not be understood by anybody who was not used to my drunken voice).

But they should not have worried about this too much because I couldn't read the menu anyway. (Unless the print is large and dark, I can't read it).

But this will not be a problem because I cannot get into the restaurant anyway. My wheelchair will not climb steps.

No issue anyway because I cannot drive the wheelchair any more. (My hands won't work).

But before that, I cannot get from home to the restaurant because the special car that I have is broken and I cannot afford to repair it. (Due to MS, I'd lost my job 8 years ago).

So better remain in bed staring at the ceiling and not try going to the restaurant for a meal.

It isn't called Multiple for nothing.

MS is like a ravenous beast which can never be satiated. I felt it was taking everything and now it was working on taking my relationship and marriage of many years.

I was feeling pretty down. I was so tired.

We with MS lie down a lot.

I was lying in bed one day listening to the radio and I heard this song.

I'm sure was not intended for me or my situation, but somehow the words spoke to me and I realised that my wife had been through so much and yet was still with me.

I was so fortunate.

So my life changing experience was to realise what she had done by asking myself what had she got out of this?

Not much.

23 years of tough relentless hardship.

And what had I? Everything.

Listen to the lyrics of the song.

Video Games by Lana Del Ray.

For the many on their backs with MS, listening because that's all they can do.

Kevin

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

People with a disability can choose the types of support to use, More opportunities to participate in the community, More rights for people with a disability, People with a disability can plan their lives and pursue their goals and dreams, The ability to receive services when needed and in the way that suits the person, Increased ability to coordinate services to suit the "whole" person/family, Minimising the number of times people have to tell their story in order to get support, Less red tape, with planning done locally by people who know their community, People with disability/family will influence the types of support and services offered, 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:

Equipment and home/vehicle modifications, Support for families and carers, In-home care and domestic assistance

I support the introduction of the NDIS.

I hope it will change the level of support required.

I agree for my submission to be made public

Regards,

Mr Kevin Stafford