From:

To: Community Affairs, Committee (SEN);

Subject: Spam: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012

**Date:** Friday, 21 December 2012 5:22:53 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.

We have a 28 year old son who contracted HSV when 1 year old. This caused major brain damage leaving him with severe cererbal palsy, severe sight impairment, spacticity and uncontrolled epilepsy. He has undergone two major events of surgery to try and remove the scar tissue on the cortex of his brain, the last 3 years ago which unfortunately caused further damage. He is listed on the DHS supported living accommodation register but we have been advised that the chance of him being offered a place is extremely low. Moreover, they advise that we should consider alternatives without being able say what they are. As his parents are 73 and 70 years old respectively we are extremely concerned about what happens when we can no longer provide 24/7 care. We have never used respite facilities because they are similarly not available when required. His father gave up his career 25 years ago to try and help improve the life of his son. As parents we have done everything humanly possible to care for our son and now believe that they should be relieved of their responsibilities before it is too late. It is critical that our son is settled into suitable accommodation asap and it is not left to the last minute. The disability system is accutely under funded and a neglected area of Government in an inappropriate Department. Disability is a health matter and should be part of Medicare at the National level and not fragmented by any State involvement. The management of Medicare is in place and disability services should be included along with all other health matters. If not most of the funding is deployed on duplication of administration at both National and State level and not improving the lives of those impaired.

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

Ensure support and equipment is available when needed, Better access to mainstream support and services, People with a disability can plan their lives and pursue their goals and dreams, Minimising the number of times people have to tell their story in order to get support

The most important services for the NDIS to provide are:

Therapy and allied health services, Support for families and carers, Accommodation options

I support the introduction of the NDIS.

Support for the NDIS is imperative for our son to have full love and care in a state of the art facility not treated as a third party citizen. However, it is critical that the funding for NDIS is used for the purpose intended and not another bureaucratic nightmare. That is, those people unfortunately impaired by fate and deserve better treatment by Government. It should not take five years to determine what disabled people require. It did not take five years to put Medicare in place. If we don't know now we will never know and it only a way to defer doing anything to correct the position.

I agree for my submission to be made public

Regards,

Mrs Margaret Crawford