**From:**
**To:** Community Affairs, Committee (SEN);
**Subject:** Spam: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
**Date:** Wednesday, 23 January 2013 1:06:06 PM

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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 care for a 3 year old with Pendred Syndrome and a 5 year old on the autism spectrum whilst also having my own degenerative neurological disorder, so I guess my husband also cares for all 3 of us while working full time.
Services in the current system are fragmented and inflexible. I am forced to receive small amounts of funding from many different sources. I currently receive support from 6 different places. This involves multiple applications, meetings, explaining our situation, and meeting eligibility criteria over and over. This not only takes up valuable time but is also incredibly emotionally taxing. Always having to think about your life in the "worst case scenario" is not healthy for anybody.
Current allied health support provided to my children is age-dependent. I am terrified of the day they are both over 6 and I have to find the money to provide their therapy. They still deserve therapy, they still need therapy. Autism does not cease to exist from year 1. They have both come so far I can not bear to think that they will regress and not live the best possible lives they can because I cannot afford $160+ an hour for speech therapy, occupational therapy, tutoring or psychology for two children.
The disability sector expects the education department to support special needs children in the public system - they do this poorly and are underfunded. School aged services provided by DSC are inadequate, wait lists are incredibly long and when you finally receive services you realise it is consultative rather than therapy based, yet you have NO choice!
I am always told I personally am ineligible for supports not provided within a formal funding plan like the FLI (such as HACC) either due to my age or the age of my children. I was turned down 13 times before Mercy Care took me on. I was told everything from "we service the aged care sector, we cannot support you for a possible 60+ years" to "we can't help you because even if having children with special needs prevented them from helping you around the house they are too young to help you anyway so you are not missing out." Nobody wants to spend their funding so they pass you to the next person yet they all agree that SOMEBODY should support you.
Nobody knows which bucket of government funding you should apply for - FLI or CAP? You are not even supported to apply for anything until you are in crisis. The system is driven by families in crisis, there is no planning for a positive future. FLI was meant to be more positive, but you are still not supported to apply unless your world is falling apart at the seams. Then after spending hours filling out paperwork you wait for months to get approval, or are denied and must start again. In the meantime there is no help.
What happens when I need to move into a wheelchair? I pay thousands of dollars for one, or I wait on lengthy lists for assistance.
Even when I receive support I do not get to choose the support I want, the support worker I want, or at what times I receive the support. I WANT to control my own life and decide what I receive and who provides it to me! I want to be able to change my supports as my condition changes and QUICKLY!
The system today is not equal. Current support received by families depends on the person they have as their LAC. Some people have great LAC's, they are well

supported and referred when necessary. Some people don't even know what their LAC is meant to do for them.

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, The ability to receive services when needed and in the way that suits the person, Removal of age barriers to services for children

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

I support the introduction of the NDIS.

The government is finally seeing that people with a disability are struggling. I am open to changes to give people with a disability a better quality of life!
People with disabilities and their carers are already incredibly stretched financially, emotionally and for time. People want control over their own lives, the supports they receive, and they want everything to be about what is important to THEM, not to a healthy bureaucrat with "normal" children. Parents of adult children incapable of self-care are terrified of what the future holds when they are no longer around.
I am hopeful that the NDIS is the beginning of a change in many services, and hopefully of the mindset of the Australian public. With review and input from people with disabilities I believe we can create a system that allows people with a disability to live the life THEY want to, and achieve to the best of their abilities.

I agree for my submission to be made public

Regards,

Mrs Samantha Powell