From:
To: Community Affairs, Committee (SEN);
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 17 January 2013 9:47:34 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 am a long term friend of the [redacted] family of more than 20 years now. I witnessed the absolute and devistating trauma of [redacted] relinquishment, upon her entire family.
I was not a parent when this occured, now as the mother of a 5 year old, I have greater appreciation of the personal cost to [redacted] and her family, especially her parents.

As a parent I know that the day will come when my son will move out of home and learn to fend for himself. Hopefully he will undertake education and training, earn a living and make an independent life for himself.

For the [redacted] family however, and for many families like them, this life trajectory is not possible.
For the most vulnerable people in our society; those with sever and complex disabilities, there is not clear line of separation or departure into the adult realm.
[redacted] requires 24 hour care, she, like many others, are unable to perform the most basic independent living skills. Sever cerebral palsy has denied [redacted] the opportunity to use a bathroom when she wishes, quench her thirst at the moment she becomes aware that she is thirsty, take herself to another room whe she becomes bored with the conversation around her, or turn over in her bed at night.
[redacted] of course would love to do all of these things. She is however, simply unable to move in a functional and controlled way, that would enable her to have what we don't even realize we take for granted.

During the years that led up to the eventual relinquishment of [redacted] care- I watched my friends physically and emotionally fold under the weight of caring for [redacted] who is a wonderful woman in her own right, but who requires 24 hour high level care.
With great dignity they tolerated the stream of carers who traipsed through their home for a few hours each week, this support so minimal in its useful, in the end added to the burden. When they felt broken beyond repair from the strain of years of broken sleep, the emotional stress of juggling full time care, running a family, providing an income, from the constraint strain of providing personal care and with such limited respite available never having the opportunity to recover from these unrelenting demands they were required to open their home to strangers and a broken service system.

In the past few years, I have become the legal guardian of a young man who lives in supported accomodation whom i have known for 20 years. This young mans family were also forced to relinquish the care of the son, when the pressure to provide the care he needed became too great. This family lost their son to a system that failed to meet his or his families needs. They remains broken by this experience, and as a result this young man who has profound and complex disabilities lives in a disability service that is not appropriate to meet needs. A recent report into this young mans care commissioned by the office of the senior practitioner, described his environment as 'impoverished'.

The proportion of the people with disabilities who have complex and high support needs such as [redacted] and the young man that I am a guardian and advocate for are limited. They are however our most vulnerable members of society and as such their lives, and the lives of their families require carefully planned services and individualised resourcing.

Every child deserves to grow up and a live separate adult life. Where their parents can be parents; not full time nurses, behaviour support workers or case managers. To achieve this we need services that meet individual needs, that support the transition to an independent adulthood. There families are integral, connections and relationships are maintained, supported and encouraged, and most importantly the rights and needs of individuals are at centre of service planning and provision.
We need to achieve this, we cannot continue to break families with the burden of full time care and then send them into a cycle of further crisis and despair when they are forced to relinquish their loved one. Who they have painstakingly supported their children with all of their love, devotion, sweat and tears until they break.

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

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,
Removal of age barriers to services for children

The most important services for the NDIS to provide are:

Therapy and allied health services, Accommodation options, Flexible in-home/outside home respite

I support the introduction of the NDIS.

People with disabilities are regularly denied the most basic human rights, such as access to shelter, safety, employment, specialized aides and equipment. If we cannot provide these basics, it seems implausible that the richer aspects of life, such as friendships, social connectedness and meaningful employment- aspects of life that we take for granted are not possible.
Disability services operate on antiquated models of care- that we would not tolerate if we were forced to access them.
We need the NDIS to ensure that individuals receive services that meet their individual needs, this surely must be a right- rather than a priviledge.

I agree for my submission to be made public

Regards,

Ms Sarah -Jane Terrill