From:

Community Affairs, Committee (SEN);

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

Date: Thursday, 17 January 2013 9:33:47 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.

Under the current system, even when a need is identified, I have to strongly lobby and argue to achieve a sensible outcome. Eq. because of a degenerative condition, everyone knew we would need a totally accessible bathroom. The ADHC OT drew up the plans for us, but when we wanted to activate that plan, the modification service said we could get by with a minor modification, which cost over \$500. A short time later we needed another modification- another \$500 and more "making do". Shortly after that, the whole thing was ripped out and the bathroom replaced as originally anticipated. Total waste: more than \$1,000. We are now waiting for a power wheelchair. We don't know how long we will have to wait, and I know that when we get the approval, it will be for the cheapest model available. This is despite the fact that my grandson will be totally reliant on his PWC from the moment he wakes each morning until he settles into bed at night. It will be sensible to get a chair that has a "stand" feature, as this will save us from having a separate standing frame, saving space and money. It will also be sensible to have a range of seating positions (reclining, tipping forward etc) as this will greatly enhance his comfort, and also help me with transfers, settling him etc. But I KNOW to get this more expensive chair I will have to fight, lobby, fundraise, complete endless paperwork etc. This battle faces us at every stage of his decline. It is hard enough to cope with seeing a child slowly lose mobility, without having to battle for every piece of equipment or assistance.

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 plan their lives and pursue their goals and dreams, Increased ability to coordinate services to suit the "whole" person/family

The most important services for the NDIS to provide are:

Therapy and allied health services, Equipment and home/vehicle modifications, In-home care and domestic assistance

I support the introduction of the NDIS.

The NDIS has the potential to remove the main stressor for families-battling for services for their child. Having a plan, and a level of certainty will help families work together with services and workers to give their child the chance to make choices, and participate in the community more freely. It should also stop a lot of waste when stop gap measures create more problems than they solve. However, I feel very concerned that this survey asks us to identify the 3 most important support types, despite the fact that all the items on the list are in fact essential to all of us at some stage. Many of the items listed SHOULD be provided as part of the mainstream services all people should be able to access. So why are they on the list?

I feel extremely concerned that the NDIS may end up being a minimum needs

document, and we will still be fighting for daily showers, access to transport and all the other things that exclude us now! We will not settle for the lowest common denominator.

I agree for my submission to be made public

Regards,

Ms Jill Coleman