

From:
To: [Community Affairs Committee \(SEN\)](#)
Subject: sub924Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 17 January 2013 1:42:45 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 have a 5 yo daughter with severe Cerebral Palsy, I live in a rural location and must travel 5 hours each way, each week for my daughter to receive adequate therapy and services. I have been forced to wait more than a year for adequate seating for my daughter even though the Drs have flagged her as having serious breathing difficulties when not positioned correctly and suggested we give her a tracheostomy. As a single mum who has had to give up her blossoming business when my daughter came along I receive 3 hours a week in respite, that is useful. HACC provide another 1.5 hours but have not adequately trained their staff so I can not leave my daughter with them. I have a son who also needs my attention and I am desperately in need of some help. There are so many things that are wrong with the current disability system, I have only named a few here but with the enormously high care needs of my daughter I do not have the time to write a huge submission outlining them all. The worst part of the system is being made to feel like you need to go hat in hand with a tear in your eye for help, it is demeaning and the service providers dole out the money in such a tight fist that we are forced to be at breaking point before any help will be given and even then we are expected to be eternally grateful for a few hundred dollars worth of respite when we really need thousands of dollars worth of respite. I find it interesting that many of the respite workers are restricted in what they can and cant do for their disabled clients with work cover and workplace policies. Yet we the parents who care for our children 24 / 7 need to do all the lifting and heavy handling of equipment and must wait inordinate amounts of time for housing adjustments, ramps, hoists and vehicles with hydrollic lifts attached and even then they are only partially funded. I have a bad back and need to go for a second operation, however I can not because I do not have enough help, money or support to be able to care for my daughter during the 6 week recovery period. I could go on and on but you get the drift - things are not working, we need more help, alot more!

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

Ensure support and equipment is available when needed, Increased ability to coordinate services to suit the "whole" person/family, 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:

Therapy and allied health services, Equipment and home/vehicle modifications, Flexible in-home/outside home respite

I support the introduction of the NDIS.

I support the NDIS, because things need to change. I would however like to address an area of concern that I have and that is that the NDIS NOT be set up using an insurance company to process claims. I have had personal dealings with both Workcover and TAC and have serious concerns that if this were done then

we would all be taking a big step backwards from the current system. The insurance companies are beholdant to no one and even after going through the lengthy and extremely stressful process of using the ombudsman and the dispute resolution they have refused to pay for services. It would be a travesty to put families of the disabled through this sort of stress to receive the most basic services required.

I agree for my submission to be made public

Regards,

Mrs Kate Casleyke