

From:
To: [Community Affairs Committee \(SEN\)](#);
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Wednesday, 2 January 2013 7:53:02 AM

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.

My 27 year old daughter has severe myalgic encephalomyelitis as defined by the International Consensus Criteria 2011. She is bedridden in a dark room double glazed to keep out noise with air conditioning as she can't tolerate heat and an oxygen concentrator. She lies with her spine exposed a Doona on her torso and socks in her feet. The drugs and daily saline she is on cost more than her disability pension. In Queensland she falls between all the cracks for assistance. She gets saline via a porta Cath but the hospital home care team only looks after patients with PICC lines. ME is not on the list for temp control subsidy for air cond. despite being very similar to MS which is. Despite being so disabled ME is not on the list for disability services and so she doesn't qualify for any in Queensland. There are no specialist ME experts or specialists interested in these patients ... So there is no real health care. The docs do a quick Internet search and suggest stuff in the UK NIC E guidelines which are refuted worldwide and in the UK by ME experts and patient groups. I have 2 nights of respite in 2 years the 63 days centre link refer to is a joke- how so you get 63 days respite for anyone with this condition .noise sensitivity is the real bugbear.

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

Ensure support and equipment is available when needed, The ability to receive services when needed and in the way that suits the person, Minimising the number of times people have to tell their story in order to get support, 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:

Support for families and carers, Accommodation options, Flexible in-home/outside home respite

I support the introduction of the NDIS.

A nationwide disability support for all Australians - cut the states duplication and give a fair go to all Australians rather than the level of help depending in where you live. We don't get support for caring for a severe ME patient no respite either . We can get counselling for the fact that we are not coping but really it would be cheaper and more effective just to give us some respite something to look forward to and plan for . A little bit of our life back. I have lost my job part if the issue was all the time I had to take off to do the admin associated with caring for my daughter.... Forms and forms and proof of this and that repeatedly the same stuff repeated assessments for every little thing. Surely once someone us not the DSP you shouldn't need to reprove your ID and tell your storey to the wheelchair people the nurses ... Nurses couldn't hang up my daughters IV bag because they weren't trained to they could access the porta Cath so it could be used .. But not actu ally use it!! Go figure? Respite care wad not surposed to hook up the IV saline because ??? So were us the respite if we have to be there twice a day to

so the saline . See the myalgic encephalomyelitis primer for medical practitioners adult and paediatric International Consensus Panel 2012 for the most up to date help with ME.

I agree for my submission to be made public

Regards,

Ms Adrienne Wooding