

**From:**  
**To:** [Community Affairs Committee \(SEN\)](#)  
**Subject:** Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012  
**Date:** Tuesday, 22 January 2013 4:04:37 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.

The service my grandson has now does but only after "blood sweat and many tears. It only took twenty years

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

Ensure support and equipment is available when needed, More rights for people with a disability, Minimising the number of times people have to tell their story in order to get support

The most important services for the NDIS to provide are:

Therapy and allied health services, Flexible in-home/outside home respite, Positive behaviour support and psychological services

I support the introduction of the NDIS.

My grandson, [REDACTED], was born a normal child but contracted meningitis at the age of seven months leaving him severely intellectually and physically disabled. He is now thirty one and living in a group home. When I read all your points I wept recalling his life over the years, every point I could tick, it is so hard to isolate just three from each section. Inadequate follow up on discharge about services was given. If you found out about a service you might get it "if funding was available" and usually it wasn't. Inadequate respite care, one group home for the entire Shoalhaven region with five beds at that time. Some helpful but most unhelpful Members of Parliament; there were not many votes in the "handicapped" (the terminology on the day) children and the bureaucrats of the education department were bullies promoting the slogan "the principles of normalisation" which meant rust bucket buses not passing registration inspection meaning the Parents and Citizens Association pleading with the Lord Mayor to run an appeal resulting in two buses (one from the Variety Club and the Paul Newman Foundation) however "we" the P and C providing one third of the cost of each bus only through the community assistance in other words CHARITY, no "rights" there to an appropriate education and of course "integration!" which meant selling off special schools as children all had to be normal! Parents of disabled children didn't have time to do "battle" with bureaucratic bullies. My grandson is in a group home some two hours from home depending on traffic and comes "home" every fortnightly weekend. He is very happy so we are too! He went to the group home when he was nineteen as my daughter was told she may never get another offer if she turned it down. There have been issues over the years mainly due to behaviour and epilepsy but these were dealt with professionally. He lives with four others who are his "friends". My older grandson was smitten with a malignant brain tumour when he was nine ([REDACTED] being seven) dying when he was twelve. Services! There were none! "Bureaucratic bullies" were involved then over respite care but our Federal MP John Sharp intervened at the most crucial time. This may be history but I will never forget. I had the privilege to hear a then Professor from Wollongong University in a

seminar on Education say "be alert and on guard". How true, it's too late once it is gone. Thank you for all you are doing and I wish you well in your endeavours.

I agree for my submission to be made public

Regards,

Mrs Gillian Dowling