

From:
To: [Community Affairs Committee \(SEN\)](#)
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Sunday, 20 January 2013 7:56:28 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.

Our adult daughter is a paraplegic and cannot stand up, so she is reliant on her wheelchair and her family for all her personal care. One of the main problems is that we cannot access the services, either they are not available or we have too high needs. The services that are there to help us, simply don't. When we inquired about help to assist with showering in the morning we were told they couldn't help us because they said it would take two nurses to attend. We asked other service providers, one said they had the funding for high needs clients but they couldn't possibly send two nurses to the one house, so the people with high needs get left behind.

We have problems getting the equipment we need. Our daughter has applied to Enable for a new wheelchair. We started the process in March last year, the chair has been approved but they are now waiting on funding and we may not get the chair till next year.

We are able to have respite, we can have either 4 weekends a year or one week a year, but we have no say in when the respite will be on. If my husband and I want to take a weeks break at a particular time of the year we have to ask for it at least 18 months before our planned holiday and then we have to wait 6-12 months to see if it has been approved.

Our daughter works five days a week but because she cannot stand up to transfer out of her wheelchair into a car/bus seat, there is no transport available to her. We have tried all the services that provide transport to people with disabilities but as soon as we mention that the transport is to take her to work, they say they cannot take her. So my husband and I take her to work and she gets a Taxi home. She has the Taxi vouchers, so she only pays half price, but we are still out of pocket \$5,000 dollars each year. We have just had to renew our wheelchair accessible car. We have had to pay \$20,000 to have a car converted to wheelchair access. We receive no help from the government, the total cost of the car was \$60,000. We now have to start saving for the next car we will need in ten years down the track.

We have no idea what will happen to our daughter when we die. We would like to see her in a group home, but there are none available, there isn't even a waiting list that we can put her name on. We have been told that to get into a group home you must be just about homeless and if we are desperate then we should just abandon her at respite one weekend. I ask you why should any parent be placed in such a position, it is cruel to both parents and child. We need more services, more group homes and the funding to keep all these things in place. +

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, 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, Accommodation options

I support the introduction of the NDIS.

We support the NDIS scheme because we need to have the funding, services and equipment available, so that the needs of all people with a disability can be met. Our daughter works five days a week, she participates in sport and she should be entitled to access services like any one else, but she is denied this. People with disabilities are valued members of the community and should be treated like everyone else. We were once told by a Private health insurance company that they don't cater for minority groups such as those with a disability, We were asking for assistance in purchasing a commode chair for our daughter. In their letter to us they said that if we wanted to go to a gym and needed a new pair of shoes they would be happy to assist us.

We really need help, no one really understands what it like to have a child with a disability and to be told that there is no help, that your child needs speech therapy but there is a three year waiting list, that because you have high needs you don't count, you don't get the service. We need the NDIS so that we get the support we need to look after people with disabilities and to have the assurance that when we are not around there will be an easy transition into supported accommodation without any other family member having the drama and guilt of abandoning our daughter.

I agree for my submission to be made public

Regards,

Mrs Sandra Smith