From:

To: <u>Community Affairs, Committee (SEN)</u>;

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

Date: Tuesday, 22 January 2013 4:50:56 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.

My 4 year old son has severe quadriplegic spastic cerebral palsy. We waited initial diagnosis for ECIS. The Scope service we had, for 12 months after albeit with fabulour therapists, was not frequent enough and they had little access to decent equipment or aids. We have had botox clinics cancelled at the last minute due to lack of public funding to the state's major children's hospital, RCH. We have now waited 6 months for his first wheelchair since agreeing to a quote. It is almost impossible to get into hydrotherapy which costs less tha \$120 an hour and which is not an hour's travel away. It is very difficult to find good physiotherapists who understand CP and are sufficiently trained that I don't spend most of the appointment explaining what the needs to them. We are now requested to use VPR centres for post-botox physio with physios who don't know or have a rapport with and which are not close to our home - why can't we use the physios who know him and w hat he needs? More funding for physio/OT/speechies training please. I am very anxious about entering the education system and the challenges there! Also we have never used respite services because it sounds all too hard to get it so we ask family for assistance when needed, if they are available.

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

Ensure support and equipment is available when needed, More employment of people with disability and less reliance on social welfare, 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:

Employment support, Support for families and carers, Case management, planning and coordination

I support the introduction of the NDIS.

I support a unified scheme which is organised and streamlined from birth, or time of disability, onwards. I support better funding of a scheme which aligns therapy, access, support (of the disabled and their carers), equipment and aid supply and distribution, employment, accomodation and education support. My son and children like him and all the other families like us, who want our kids to all have TRUE equal access of every type to life, love, jobs, happiness, recreation, technology, education and a fair go.

I agree for my submission to be made public

Regards,

Ms Rachelle Burgoyne