From:
To: Community Affairs, Committee (SEN);
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Friday, 25 January 2013 2:46:23 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.

As mother and carer to my 20 year old son who has PWS, Prader Willi Syndrome, in my opinion Disability Services Qld has always been badly managed, proven unfair assessments, fragmented services and poorly underfunded in our location compared to other locations in and around Brisbane. Because of this my son was not provided ANY Post School Services funding however, other PWS children did receive funding ONLY because of their domicile. PWS Mothers in and around Brisbane all know each other as do we know all our PWS children and young adults. The HURT my son has suffered because of the unfair funding of DSQ regions is criminal YES, it goes against the UN Convention on Rights of People with Disabilities, ratified by Australia in 2008. My son is given NO choice on the direction he wants his life to head. We had to fight to get PSS funding. It was fight or lose our hope for the future. What justice is there for people with disability? My son was given no choice when he left school. He would have to stay at home everyday. I would have to resign my job to stay home and care for him. I would have to be paid a pension by the government, lose our home and live in a caravan park. My other adult children would not be able to live with us anymore. Figure this out - resign my job & pay me a pension OR provide PSS funding for my son - keep my job and home and our family stays together. YES WORTH FIGHTING FOR. My son wants to be like his sisters and brother. He wants to make his OWN CHOICES and contribute to his future goals. My son cannot read or write but he does understand what is best for him however he needs help to access resources and even for me as his mother it is extremely difficult and very time consuming to get through the maze of government red tape and form filling. Then you find that dept has been re-named or integrated within another dept or some other such thing!

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

People with a disability can plan their lives and pursue their goals and dreams,
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:

Employment support, Accommodation options, Flexible in-home/outside home respite

I support the introduction of the NDIS.

It will give my son choice. There will be services available to him that were not available to him before. He can use services he needs, NOT what is left over. He CAN change his mind and won't be locked in to something he has out-grown. He can get a paid job, something he really wants to do. He will have more independence. He will have a say and be HEARD and be treated with RESPECT. DSQ people won't be able to make decisions on his behalf anymore. His selfesteem will be so much better and depression will not be so much of a worry. His world will be positive and good and he will be able to manage decisions himself with some help. There will be hope he can live independently with support and that support will be available to him. I will be able to die in peace knowing my son will be fine.

I agree for my submission to be made public

Regards,

Ms Lachele Knowles