From:
To: Community Affairs, Committee (SEN);
Subject: sub974Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Thursday, 17 January 2013 3:18:28 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.

Our son is 22. He has Aspergers syndrome. There was disagreement about the diagnosis which was difficult to understand. While there is plenty of support for children on the Autistic spectrum, adults do not fare as well. He had 2 years of Transition-to-Work (TTW) but this has not secured him employment on an ongoing basis. After completing TTW, he joined a Disability Employment agency. He did not find work with them. They spent much time planning, organising a resume and looking for a position for him. But no work eventuated. After this he joined a different Dis. Employment agency. He secured work for a finite time of 6 months. He was fantastic at prioritising his job in his rather chaotic life. He can do it! Now he is again without work, although willing and wanting to work. In March he will finish with his current agency and compulsorily join another job agency and start all over again! What a waste of time and effort. I have written to his current agency, pleading with them to help him find work before his time with them expires, so that he doesn't have to languish for months between now and when the next job agency can organise work for him, after a prolonged initiation process - again. How will he survive when we are no longer able to give him food, shelter and, most importantly, our unconditional love and support. What will there be for him? Months of no job, interspersed with a bit of work here and there, but no continuity? Expensive psychiatric care when the stress of life is too much? He feels stressed and overwhelmed easily - it is part of Asperger's syndrome. He needs expensive medication and the support of a psychologist and psychhiatrist. How will he afford this and who will take over my role as his mother and advocate? It can be a full-time job, but this is not apparent to an outsider, or even to him. I spend many hours each month working as his back-up support and voice. I want someone to take over this role ev entually, because I don't know if he can survive without this support. It is very frightening to contemplate our son's life when we are no longer here. He needs security, support, a job, a permanent address and someone to oversee that his needs are met. None of this will be possible without financial support and it will need to be far more than the current Disability Support pension. He has a sister. Will she be expected to pick up the pieces, like her parents currently do when things fall apart for our son? Will the frustration and difficulties continue when we are no longer here? Let me tell you, it's exhausting. Please help our family and countless others - we deserve it, don't we?

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

Better access to education and work opportunities, More employment of people with disability and less reliance on social welfare, People with a disability can plan their lives and pursue their goals and dreams

The most important services for the NDIS to provide are:

Life-skills, Employment support, In-home care and domestic assistance

I support the introduction of the NDIS.

Why would I not support the NDIS? Why would I leave my son in the difficult situation where he is now - registered with a Disability Employment agency (the second and about to join a third - it's a compulsory government move) but not much job prospect so far? Living on the Disability Pension which we are forever grateful for, but he will never know the same standard of living that he has grown up with on this amount of money? Bouncing from job to job without any continuity or security? Wondering where he will find the money to pay his psychiatrist, psychologist, medical bills and medication which his parents now pay, but he could not afford? Finding himself with no money to pay for food, transport, entertainment? Having nowhere to live affordably and safely with the security which we all need? Feeling alone and abandoned, overwhelmed and unable to cope due to the effects of his disability (Aspergers syndrome)? He does not realise yet how difficult life could be fo r him without the love and support of his family. He takes for granted the roof over his head and food in the fridge, but how will he pay for this, as well as medical bills and allied health professional assistance when he has a crisis in his life? We have supported him and will continue to do so as long as we live, whatever the cost, but this won't sustain him when we die or become unable to support him for health or other reasons. Would the government of Australia want this for their family member? I don't think so.

I agree for my submission to be made public

Regards,

Mrs Joanna Wagg