From:
To: Community Affairs, Committee (SEN);
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Monday, 14 January 2013 9:19:18 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.

The services are fragment. I could accuse the current system of attempting to hide the services available to us for our intellectually disabled son. When we have asked this question the answer is virtually that "We are not permitted to tell you". The question that can be answered is "Is our son entitled to ...". To find out these questions we have to go to case managers and to the families of my son's peers.
My son was diagnosed with the disability as a toddler when we were working in Holland. As soon as the condition was diagnosed the government services kicked in - we had coordinated intervention services in the home on a regular basis, and I am convinced that my son's needs now have been reduced by this early intervention.
When we returned to Australia we found no coordination of services and no where to start. When we did find intervention services through word or mouth from friends of friends we were obliged to put his name down on long waiting lists. Most parents are able to put their children onto these lists from birth, but my son was 14 months old when I returned from my assignment in Holland. Later we faced lists for toilet training and devices for toilet training. We did get a moisture alarm, but it was broken and inclined to false alarm - and there were none that could be used to replace it. There is a window of opportinity for toilet training - when the disabled person becomes too old the habits are entrenched and we know some disabled people who are considered almost impossible to train. It may not seem like a big deal, but in terms of the self respect and mobility of the disabled individual, his family carers and respite workers it is huge.
Privacy rights and the rights of individuals have gone to far in the case of my son. He cannot give us power of attorney because he is non verbal and could not be shown to be giving it to us with full knowledge. We as parents of an adult with an intellectual disability are his defacto guardians but we can find no way to become his legal guardians. We believe however that the State could become his legal guardian but it seems we cannot. This has many impacts. It was difficult to get the pension for him and it is imposible for us to get records of his medical expenses from Medicare and Medibank so that we can include them in our taxation. By denying his family the rights that he is not able to assume, he is being denied those rights.
Council respite services vary in their usefulness. We have experience from two councils. In Moreland we could use the service. We were entitled to an allocation that gave us a few hours on one day every week so that my wife could take another of our children to lessions that out disabled son would not sit through. There were a few hours left over in the month which allowed my wife an I to go out one night a month to dinner or a movie. We have no family in Melbourne and it was difficult to go out unless our son was being cared for by a trained professional. When we moved to Darebin, the support services looked good on paper but the allocation was so inflexible that we could not use them.

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, Access to reliable information about support options

The most important services for the NDIS to provide are:

Therapy and allied health services, Accommodation options, Case management, planning and coordination

I support the introduction of the NDIS.

Efficiencies and experience gained from the coordination and provision of services through a single specialist authority.
The system is fairer because it can help all - regardless of the cause of the disability.
Some of the care and responsibility that currently falls heavily on the family and the individual is shared with the community. I have seen in the extreme families that could not cope and have reluctantly walked away to force the primary care onto the government. If families have more support there are potential savings with fewer families having to make such decisions.
Early intervention and rehabilitation that can sometimes more than offset future costs of a disbility that has been initially under-treated.

I agree for my submission to be made public

Regards,

Mr Peter Woodruff