

**From:**  
**To:** [Community Affairs Committee \(SEN\)](#)  
**Subject:** Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012  
**Date:** Wednesday, 9 January 2013 2:26:20 PM

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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.

I do not access services myself but have been a provider and an advocate for those who use them through my role as an educator and a board member of NGO involved in employment options for people with disabilities.

I have also been a supporter and advocate for both my parents who required these services before they passed away.

In both situations I was necessary to these people as the system was very difficult to navigate and availability of services was not clear and often hidden if you did not have understanding and regular contact with the existing systems.

Some government agencies were also very dictatorial to some of the parents I worked with, offering absolutely no options other than the one the agency decided were suitable, particularly when it came to choices around where a young person should reside after they turned 18 years. Most young people choose to live with other young people, not their parents or a middle-aged carer. These are the only options allowed by a Federal Government agency for some young people with a disability in our MidWest community.

I have also been witness to one person with intellectual disabilities become too old to actually manage physically in a group home and no longer able to work at such institutions as Activ being placed in the dementia section of a local nursing home with no diagnosis of dementia.

She had no family to advocate for her.

I also tried to assist another person with an intellectual disability who, with the assistance of the local health service in her small MidWest Local community, cared for elderly parents until they passed away. Her parent owned the home and this person could have managed to continue to live in this home and her community. The services were keen to support this person as they saw her as a valued member of the community.

Her siblings together with this Federal Government agency were able to override her choices, dispose of the family home, place her in a nursing home in a metro area 500kms from where she had lived and moved freely all her life. Those working in the health service who tried to advocate for her had their jobs threatened with such rules of breach of confidentiality when they tried to advocate for her.

When I contacted the agency to protest I was told there was nothing they could do. My point here is as they are appointed to represent people with disabilities. They failed to do this over assisting the family with their wishes rather than the person with the disability.

In the case of my parents no services were readily offered or obtained. Investigation, applying and obtaining them was incredibly difficult and they would not have been able to do this without our support so I cannot imagine how it is for someone who does not have the support of family or a friend.

In my existing role I attend community road safety community meetings where changes to public transport arrangement have been agreed and implemented completely reversing an arrangement put in place to accommodate people with mobility disabilities (in our community we have a large number of people with disabilities using bus transport as mode of accessing the community). The local government, the bus company and the shopping centre were able to make these changes as the traffic issues affected a larger section of the community and the people with the mobility issues represented a minority group in the community. Therefore their need became secondary. These changes were made with absolutely no provision for this minority group of people who in the future will find it far more difficult to access this shopping centre.

I need to highlight that in present day Australia that attention to law and provision for people with disabilities is generally only required to be addressed when there is a solution. We are still in a time when access is not mandatory for all facilities.

With my work I have tried to arrange visits to some communities for people who provide valuable presentations around their adverse experience with road safety and have as a result limiting physical disabilities. The visits have not gone ahead in some communities as the accommodation does not cater for people who require wheelchair access. Some of the facilities have been upgraded recently and still the building by laws do not seem to include the necessity of such essential facilities. It seems the provider of such facilities still has a choice about discriminating against people with such disabilities.

The issues are complex but I believe at this point in Australia that 'lip service' is paid to a person with a disability being able to make choices about how they live. Ultimately and frequently, they find themselves in a situation where the solutions are chosen for the convenience of the family, the agency, local government or the community not what they would choose for themselves.

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

Ensure support and equipment is available when needed, Less red tape, with planning done locally by people who know their community, Removal of age barriers to services for children, 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:

Accommodation options, In-home care and domestic assistance, Case management, planning and coordination

I support the introduction of the NDIS.

Already the vigorous discussion around the scheme has raised the profile of the plight of this very disadvantaged section of our society. The public sector including parliamentarians have been unable to avoid listening to and reading about the many different situations and how difficult it is for these people to lead some semblance of decent existence. This must advantage their case and stir others to advocate more vigorously for them.

I am hoping the scheme will not only provide funding but a more accessible system with the person with the disability and their family if the case may be, actually having a choice that suits them more not what is convenient for those working or providing resources for them.

I am also hoping that one of the secondary benefits will be that legislation for provision for people with disabilities access within our Australian total physical environment will become mandatory and also amended retrospectively if required to allow access.

I agree for my submission to be made public

Regards,

Mrs Kate McConkey