From:
To: Community Affairs, Committee (SEN);
Subject: Submission to the Inquiry into the National Disability Insurance Scheme Bill 2012
Date: Friday, 25 January 2013 3:58:16 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.

I have a brother (aged 26) who acquired a brain injury at 5 months of age due to a meningitis infection. He also developed severe epilepsy as a result. As [redacted] brain injury occurred at such a young age, prior to learning any lifeskills, he should have had access to skills development services, including communication and social interaction. However, due to living in a rural area of Tasmania, the only services offered to my parents at the time of [redacted] acquiring his injury was for them to travel to specialist services more than 130km away - an impossible ask for a family raising six children under the age of ten on a low/self-employed.

In 26 years, we still find it is extremely difficult to access any services, primarily for the following reasons:

There is only one major service provider based in our local area, and this provider has refused to provide a service to [redacted] (we have a case coming before the Anti-discrimination tribunal, as this provider withdrew all services after an incident in which [redacted] caused a soft-tissue injury to a support worker whilst in a complex-partial seizure state. The service provider has refused to accept that [redacted] actions arose from his disability, despite having assessed his as having the potential to be extremely violent. This provider had put no mechanisms in place to protect their workers or [redacted]). Because of our isolation, it was extremely difficult to find another provider to take [redacted] as a client. This was eventually achieved by finally (after seven years on the wait list) being allocated a small individual support package (ISP). Additionally, this one local service provider is also brokered to provide Commonwealth Respite Services in our area - we cannot access respite services because of this.

As the current system provides funds to service providers rather than clients, there seems to be a culture amount some disability service providers (including the one mentioned in the paragraph above) to "weed out" the difficult or challenging clients. [redacted] has many challenging behaviors due to both his ABI and epilepsy, and this is why he requires a high level of care. However, with funding being allocated to agencies, if they find they no longer wish to retain a difficult/high care needs client, they can simply "dump" them and allocate their funds to someone else less challenging. This results in (and [redacted] case is a perfect example) clients who have the highest needs of support actually receiving no support (particularly in remote/rural areas where there is only one provider). This has to stop immediately.

Due to [redacted] level of disability and medical needs, he requires two support workers (or a support worker and a family member) to be with him at all times. This means that although [redacted] has been allocated 14hours a week ISP, this only equates to 7 hours of actually support. this provides very little respite for my aging parents who provide care for [redacted] 24 hours a day. (My parents have ongoing health problems - hernia, cataracts, depression, anxiety, foot problems, back problems, etc which they have not sought help for simply because they cannot take the time to go to a doctor or specialist).

There are no supported accomodation facilities in our local area (as far as I know the closest would be in excess of 120km away). This is causing great stress for myself and my parents when thinking about [redacted] future accomodation needs (for when my parents are unable to continue to provide care). There needs to be

supported accomodation in small rural townships where the person with the disability can remain living in an area that is familiar to them (particulary important for those with cognitive disabilities such as ABI), and are able to continue to access their natural supports (which can include anything from social access to family and friends through to attending a cafe that knows exactly how they want their cuppa or police officers who know that certain "socially unacceptable" behaviors are simply an attribute of a person's disability).
There is limited or no access to mental health services for people like [redacted]. After the major 2006 East Coast Tasmania Bushfire, I tried to obtain mental health services for [redacted] as he suffered anxiety (the Bushfire came within 400m of his home). After spending half a day phoning one service after another and being sent around in circles, I gave up trying to get professional help for him, and instead developed my own program to assist [redacted] recovery (mainly role-playing attending a fire as I am a volunteer firefighter and pretending to communicate back to base how we were extinguishing a fire and making everything safe). It took about five years for [redacted] to recover to a level that I am happy with.
The seems to be a culture of relying too much on family members to provide care. Over the years, I have given up much paid employment to assist in [redacted] care. For example, in a period of three years, I had to give up paid work for a total of 11 months to give my mother a break from caring to to focus on fighting to obtain the small amount of service we are currently receiving). I am a low-income earner and am in my mid-thirties, and have very little superannuation. This makes me very worried for my future.
There are many other issues I would like to discuss, but because I am an extremely busy person (and give every spare moment to caring for my brother and parents), I am unable to write more.

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

Increased ability to coordinate services to suit the “whole” person/family, People with disability/family will influence the types of support and services offered, 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:

Life-skills, Recreation and community access, Support for families and carers

I support the introduction of the NDIS.

This is the only way for Australia to recognize and respond to the needs of family carers (particularly those who are aging) and the needs of people living with a disability. The NDIS should provide access to services to all who need services no matter where they live and the type of disability they have.
The NDIS needs to have assessment processes that allow aging carers to be assessed alongside the person with the disabity - this will ensure that the appropriate level of care is provided and that the government no longer exploits the love and sense of duty of family members. Also, supported accomodation needs to be open to having facilities where both the person with a disability and their aging carers can reside together and receive the services that both need, rather than sending the disabled person to a support facility and the aging carers to a nursing home.
The NDIS could offer the opportunity to provide tiered payments to support workers who care for clients with high care needs (particulary challenging behaviors). There is currently very little incentive for workers to accept work with challenging clients. Additionally, there may need to be increased funds offered for people living in rural/remote areas - we currently use some of our support hours

to cover travel time for support workers (some of whom live in excess of 150km away), as we can only access one local support worker and the other workers must travel excessive distances. If extra funds were allocated to rural people, this could be used to cover travel time for support workers and thus encourage them to accept clients living in remote areas that might not be able to access local workers. This will also open up opportunities for rural people to choose their provider rather than simply accepting the one and only local provider (who might not be able to meet their needs).
Again, I could say much more, but do not have the time.

I agree for my submission to be made public

Regards,

Miss Hannah Rubenach