In favour of a National Disability Insurance Scheme (NDIS)

Life with my 17 year old daughter who has Rett syndrome

I have a daughter with a complex neurological disorder, which causes her to be totally dependent on others for all her daily needs. She cannot walk, talk, eat by herself, shower or toilet. She also has complex medical needs, such as epilepsy, reflux, osteoporosis, chest infections requiring frequent hospitalisations, etc.

Life with my daughter is a daily struggle and I believe a National Disability Insurance Scheme could at least alleviate some of our issues and problems.

1. Diagnosis

There was no support at the time of diagnosis, we were sent home from hospital and told that there was definitely something wrong with our daughter, but that they could not tell us what and someone would get in touch with us. This took several weeks, and by that time we had already done some research ourselves, as we found it impossible just to wait and do nothing.

Solution: There should be a contact in every hospital whose role it is to support families with a newly diagnosed child. This person, e.g. social worker, would provide the family with information and direct them to services. There should be a central contact point for disability services and no one should fall through the cracks of the system, because it is too complex to navigate, which is the case now.

2. Early Intervention

There should be suitable and easily accessible early intervention programs for all children. This will help them develop to their full potential and will support families in those difficult early years. It will also save a lot of money down the track.

3. Aids and Equipment Program

When our daughter was 18 months old, she needed a gait trainer to teach her to walk, but there was no funding available for one of those, costing over $3,000. When she needed her first wheelchair, we learnt that there is funding for wheelchairs, but never for the full cost and often with long waiting lists, which means, we either had to supplement hundreds or thousands of dollars or we had to go begging to philanthropic organisations, in the hope of getting some gap funding. This has been an issue every time she has needed equipment:

- Wheelchairs (3)
- Shower/commode chairs (2)
- Hoist (1)
- Standing frames (3)

only to name a few. And then there was the expense for our first wheelchair accessible vehicle, without any funding, which cost $35,000 second hand and our second wheelchair accessible vehicle which still cost $30,000 second hand after deducting the funding for the wheelchair modification.

Families and individuals with disabilities should not be punished for their already difficult situation with exorbitant costs for absolutely essential equipment.

4. School and before/after school and holiday programs

Our daughter goes to a wonderful special school, which we are very happy with. But we soon realised that there are no before or after school programs for someone with her needs and the only school holiday program, where we can access one or two days per holiday if we are lucky, is way out of our area. This makes being in the workforce extremely difficult. Children with disabilities and their families should have the same rights as other children and families.

5. Respite

Our daughter has been accessing a wonderful respite house called Very Special Kids for children with life threatening conditions. However, this respite is not government funded and relies heavily on fund raising. It services several hundred families in the whole of Victoria and therefore respite is scarce. We will also lose access to it once our daughter turns 18 next year and there is no equivalent for adults with her needs. We have been on a waiting list for another respite house for over a year and have not moved forward. A lot of respite beds are taken up permanently by homeless children and young people with disabilities and therefore families who are still caring for their family members with disabilities miss out.

There is a desperate need for more facility based respite!

6. In home support

For years, we have had to fight for every hour of in home support, be it personal care or respite. Without any family support, with a child who cannot be left with a regular “babysitter”, this has been extremely difficult. With our already extremely demanding and stressful lives, to not even be able to go out for a meal or to a movie without a lot of planning has taken its toll over the years.

7. Day Programs

Our daughter has one more year at school and we will then have to find a day program for her, which can cater for her complex high support needs. There are not enough of these programs and the existing ones are bursting at their seams but new ones are not being created. These programs are funded about half of what special schools get, which means they cannot employ enough staff to provide quality programs. In addition, these programs often do not provide transport for their clients; consequently I might have to start transporting my daughter to her program for a 9 am start and pick her up again at 3 pm. This will make my being in the workforce even more difficult.

There is a desperate need for good quality centre based day programs for individuals, who cannot hang around shopping centres, parks and libraries all week!

8. Supported Accommodation

My daughter will never be able to live independently. I am getting older and my body is tiring of the daily physical care I provide to my daughter. I have already had two shoulder operations and constantly suffer from lower back pain and other problems. I am also constantly fatigued, physically and emotionally. I am over 50 years old and would like to have some independence again at some stage in my life, something other parents take for granted. However, I am unable to plan for my daughter's future. I cannot say that when she turns 21, I would like her to move out and live in supported accommodation, somewhere close to her family. All I can do is provide the Department of Human Services with a Disability Support Request, stating that I would like accommodation for my daughter, and then it is the luck of the draw. It could take a few weeks, months or more likely a few years till a suitable vacancy becomes available. This worries me no end, causes me sleepless nights, of which I have had plenty in the 17 years of my daughter's life.

9. Superannuation for carers

As I have been my daughter's main carer all of her life, I have only been in the workforce very part-time. I have very little in terms of superannuation, as a result of having saved our government and society a fortune by fulfilling my full-time carer role! This would be an issue for most carers.

A National Disability Insurance Scheme could provide adequate funding for the needs of people with disabilities and their families. If there was enough funding, services could be planned properly and the system could move away from being crisis driven and constantly providing bandaid solutions at exorbitant costs.