

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Name suppressed
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Partially
Confidential

I am 53 years old, and have been living with multiple sclerosis for over 20 years. The MS started out as Relapsing Remitting however, progress to become Secondary Progressive in the year 2000. Unfortunately, I became completely paralysed (from the waist down) around the year 2009/2010 and my husband () cared for me in all aspects needed. That is, all personal care (bathing, toileting and dressing) until I had a stroke in July 2015. It was then that the State government, NSW allocated me funding through enable to cover personal care etc. It was only then, that we ever received any assistance at all.

My husband, is 11 years older than I and is in recovery at () Hospital, Sydney from open heart surgery recently. Whilst he has been in Hospital, I required care morning, afternoon and night (putting me to bed). I have been technically deemed to be a two person High Care client. My husband, was acting as the second carer.

During the months all on that he has been in hospital, I have required to pay an extra carer every time I do anything. Also, I need to have somebody stay in my house with me overnight. I have been trying (through my Local Area Coordinator for NDIS) to access some sort of emergency assessment. My almost 65-year-old husband is also overdue for a knee replacement. At that time, I will also need 24/7 care. Trying to find information or contact phone numbers to cover these situations on the NDIS Website, is very difficult.

Also, when I was assessed by an NDIS Assessor (), she had recommended that I needed a new motorised wheelchair to enable me to interact successfully with my local community and friends. The wheelchair, that I currently use (supplied through Enable N.S.W) cannot fit through standard doors, nor can it access community transport options? In order to move round, I found it necessary to purchase a secondhand Toyota coaster bus (former nursing home one), with side/rear lifter wheelchairs. That is the only way I can leave my property, which is 15 km from my home town of (). The little village I live in has no shops or services. In other words, I am completely isolated. As a former singer/entertainer in Sydney the latter very active life prior to becoming disabled, I find this completely disheartening. I have suffered and continue to suffer from gradual mental decline, due to the inability to access my friends or activities.

The wheelchair, which was identified as being suitable costs \$36,000 upfront. The funding allocated under my budget, was only \$18,000? Also, with my husband due home very soon, I needed in order to care for him. The chair identified suitably, was a scissor lift which enabled me to access everything on the existing kitchen bench. Also, since my stroke in 2015, I have not slept in the same bed as my husband. That is three years almost now. This is not acceptable for a married relationship.

Basically, I have found that the time NDIS has not met my initial expectation (from the initial publicity when announced by Politicians). Everything is restricted by Bureaucratic paperwork and thus takes an inordinate amount to access anything. Attached, part three OT assessments for necessary equipment which would enable me to live comfortably in the future. One of them is a ceiling hoist (with motor). This piece of equipment alone, if installed ASAP would negate the cost of a second carer seven days a week. Compared to the cost of two carers, with this hoist, I would only require one carer. It is a more efficient and inexpensive option.