

I am contacting you today regarding the NDIS. I have sent a letter to the previous Prime Minister Mr Turnbull, but I don't think he really understood what I was trying to say. As he referred my letter onto the Minister for children's services, who did reply and suggested I enquire about NDIS and to look into a plan for my daughter. Just to set the record straight I am very aware of how to apply for NDIS plan and all that entails. Now to express to you my concerns about the NDIS and little about me so you can understand hopefully what I am on about. I am 61 years of age and married for 40 years. We have 3 adult children one who is 34 and has Downs Syndrome, she is severe, as she suffered lots of health complications at birth, 8 weeks premature, and heart failure, she also has a twin who fully qualified Chef and who does not have Downs syndrome and another sibling who is a Secondary High School Teacher. My daughter is unable to talk, non-verbal, and is unable to dress herself, bath herself, toilet herself. My husband and I are her primary carers. My daughter attends a service provider 5 days a week 9am to 3pm to help her with her social skills and day to day life. Prior to NDIS we had available a thing called RESPITE which she could go, and give myself and my husband a well-earned rest so we could recharge our batteries. We could also book her in for a maximum only of 5 weeks so we could go on a well-earned holiday. This thing called RESPITE was a life line for us, from the time she was a toddler. My daughter loved to go there and was well cared for, so this all meant everyone, she and her parents were all happy. Then along came NDIS, and someone decided that RESPITE could be part of this, and be in a plan for a person, but the name RESPITE was changed to SHORT TERM ACCOMDATION, still at the same venue.

Now, the price, this service provider charges are weekdays \$657.10 per weekday night, Saturdays \$788.77 and Sundays \$949.70. They are well within their rights to charge these amounts as they are the recommended prices set by the government. Unfortunately, when one goes to a NDIS plan review meeting, the people doing the interview do not understand the importance of carers needing time off from caring for their loved ones, so they don't approve the funds for this. Last year at my Plan Review for My daughter I requested 40 days of Short Term Accommodation, do you know what they gave her 40 HOURS, now how sad was that. Wouldn't rectify it at all, we just had to take it, and deal with it. Now I work 24 hours a week part time permanent have done for the past 17 years, my husband has full time work for 48 years. We both pay our taxes, and work hard, and care for our disabled daughter, we don't claim carer's pension. My suggestion is SHORT TERM ACCOMDATION or what it really should be RESPITE should not be on the NDIS as it really is for the carers, so we can have a break to recharge our worn out batteries, so we can continue to provide care for our daughter who needs us to be well and healthy and mentally strong. Another thing you need to be made aware of is people in their plans are not getting funding or enough funding for SHORT TERM ACCOMDATION, so therefore the service provider is only able to open their house on a lot less days, so therefore accommodation is very rare these days, and one is very lucky to find a day when they are open. As they don't have clients, because their clients aren't being funded. Can't you see how stuffed up this is. We are honest hardworking people with a disabled daughter, we are getting old, we can't get respite on a regular basis because the NDIS has destroyed this for us. What would you do. Do you think this is fair. We don't complain about anything, but our daughter is very precious to us, we want to be able to care for her as long as we can. We need a break from time to time.

The respite home was once funded by the government and the clients only paid a small fee per night. Why not go back to the way it was. I was delighted to hear you will engage a minister for NDIS. Please also consider feedback of carer's journey of the NDIS the trials they have incurred. Consider having ordinary everyday people on NDIS Advisory Committees who know first-hand what it is like to care for a disabled person and what this person's needs are. I have attached a photo of my dear Kathryn, having her feet washed at the Lord's Supper this year. It has always been hard to bring Kathryn to Church, as she would misbehave and be very vocal, which was hard. But for the past couple of years I take her, she is so well behaved, and when the Parish priest asked me if she could be included in the Washing of the feet ceremony, I was very nervous, but she was just wonderful, and I don't think there was a dry eye in the church. Please consider my thoughts and change this system regarding respite for disparate families, take Respite (Short Term Accommodation) out of the NDIS and return it to the way it used to be funded prior to NDIS.