My name is Catherine Murray and I care for my 22-year-old son, Jonathon at home. I was 25 years old - young and healthy - my husband and I awaited the birth of our first child with the normal hopes and dreams that every young couple has. Sadly we were to be devastated when Jonathon was born with severe multiple disabilities. I had no time for depression - I loved my son with a passion and quickly set to work to understand his disability and to find the most effective therapy and health care plan for him. I took this job very seriously and as my husband has always been self employed and worked 7 days a week the work load was massive, back breaking and unrelenting. My son's disability was not genetic - just bad luck - so we allowed ourselves to have another child. Our daughter was born 3 years after Jonathon and thankfully was healthy. She has just turned 20 and has never known a normal family life - we could never afford family holidays, respite was always difficult and severely limited and Jonathon's health was always a factor that greatly reduced quality of life. The massive stresses logistically, financially, socially, emotionally and physically can never be underestimated or indeed understood unless you have walked a day (22 years would be better) in my shoes.

22 years ago institutional care for the profoundly disabled was greatly under funded, understaffed and abuse was not unheard of. The horror stories that I was told of and the abuses and degradation that I witnessed first hand drove me to research care options. Greystanes Children's Home in Leura seemed to have a good reputation and we as a family made the move to Wentworth Falls - 5 minutes from Greystanes to access once a year respite and to be close to permanent care if we had another child or physically the task was becoming to difficult. I could not abandon my beloved child into care and sadly made the difficult decision not to have another child - no son for my husband or indeed no sibling that my daughter could run and play with, grow up with and look forward to having as a friend later in life.

Jonathon grew larger and his disability was becoming greatly exacerbated - his body was deforming at an alarming level. His uncontrolled epilepsy was life threatening and a constant stress to family life. He suffers cerebral palsy, profound scoliosis, leg and foot deformities and contractures. He cannot weight bear and it takes 2 people to hoist him into bed, wheelchair, at every nappy change, dress and to turn him. He has suffered pressure wounds and this is a constant stress. He has suffered serious falls and injuries at school - never in my care. He has endured 4 operations to try to lessen his physical deformities - including massive spinal surgery. All as private patient with me as his round the clock nurse. Disabled people come last in hospital waiting lists. Thousand of dollars is needed to augment the cost after the private health premiums.

Several years ago we were told that the State Govt of NSW was devolving Greystanes in favor of group homes. Very generous packages were available to encourage parents to take their institutionalized children home - including modified cars, home modifications, specialized bathrooms with hi-low baths, ceiling tracking ect. An alarmingly low number availed themselves of this generous offer. Some did accept and massive expense was borne by the Govt only for the child to be handed back for a place in a group home. Very large amounts of money was wasted in buying properties with expensive modifications only to find that the property was unsuitable - this house is currently empty, as the residents have been moved to another group house that had gone under renovations. All this massive expense was for the residents of institutions - those who were kept at home have missed out entirely. We were promised a respite facility and indeed this false hope was what we believed for many years as the devolution went ahead. It was during this time that my husband suffered a massive stroke. During this crisis Greystanes was able to care for Jonathon. The stress would have been totally to much for a mother to suffer if I had to worry about my son's welfare while my world was crashing around me with the realization of the severe nature of my husband's stroke, his rehabilitation and the acknowledgement that financially all our hard work over 20 years was being severely compromised.

This massive strain continued and I took Jonathon home and settled in to care for him while attending to my husband's therapy. My husband suffers epilepsy along with other cognitive and speech problems. It was at this point that the NSW Govt cruelly decided that they would not provide respite as part of the Greystanes devolution. We would have to take our chances in a dept. run group house that has never catered for the profound before. No modifications were carried out and to date they still have not been carried out. The house has a history of violent bed blockers and their safety has never been guaranteed. None of our concerns have been taken seriously. I took my story to Stateline and undertook a petition to garner support to urge the govt to accept Greystanes offer - they will buy a respite house if the govt will fund staff. 5 months has elapsed and all I have received is a "thank you for your LETTER' - I am not impressed.

The NSW Govt recently announced its 10 Disability Plan - future dollars - it claims consultation but it is yet to value my input, my sacrificed life, the MASSIVE DOLLAR SAVINGS I HAVE BEQUEATHED THEM. I am treated with contempt - no information is forthcoming - no reassurance is given. I have asked if I could possible have a holiday next year - Jonathon will 24. I have never had much more than a weekend away and I think that I deserve long service leave considering the massive strain that my family and I have endured. The answer is "I don't see how we could organize that". Specialist care is years away and in the form of a 5 bed respite facility in Ashfield (1 1/2 hours away). This is meant to service the State?

All this stress and the fact that I am worn out physically, mentally, emotionally, financially, socially and spiritually. Both the Federal and State Governments have failed me. All I receive from the Federal Government is $90 per fortnight. No tax cuts to care for a profoundly disabled 22 –year- old. He has just been assessed for day programme - he was rated as exceptional care (only 3% will be rated this high). If he was in a federally funded nursing home - he would attract the top level of funding - a massive expense. What have I saved Governments over 22 years? - my care is cheap and I care for him in a private hospital with me as a principal nurse when needed. Am I feeling undervalued - YES, YES, YES. I am devastated that I sacrificed my young life to care for my beloved son - happily - as I love my son with all my heart but I can’t help but realize that by keeping my son at home and undertaking his care I am actually worse off, I can not take this level of stress for much longer - there is a limit of how much stress, heartbreak and worry (along with back breaking hard work) that a five foot mother can endure. I have put my name on the waiting list for permanent care for Jonathon in a group home. I am absolutely devastated that I need to do this - I was always of the opinion that I brought my son into the world - I shall care for him. Alas NSW has no waiting list - they will publish them for fear of total humiliation - they would not want to advertise their massive underestimation of the need for permanent care for the profoundly disabled as the carers age. No one can tell me if and indeed when a place will become available. Obviously I do not expect a date - but I would like to know if could be years - a waiting list could indicate the extent of the problem. One local child not nearly as difficult to place as my child took 5 years to gain a place and this was when there was not this much-unmet need in the community. As my child in not "dumped" an emotive term but I call it as it is and he is not in bed blocking respite care he is a last priority for the NSW govt.

I shall conclude by stating that I am trying to be constructive - I have had over 22 years experience of profound disability and have witnessed at first hand the impact that disability has on the primary carer and the family. I am fully aware that I have been extra ordinarily unlucky and I do not blame any government for this bad luck but I do blame both federal and state governments for failing me at a time when I most needed help. Both have shown disregard for the impact financially and physically on my family and me. I should not have to beg - yes beg for the surgeon to operate on my child at a slightly reduced co payment. There have been other degradations that I have personally suffered that are so personal and painful that many years later I could not bring myself to write of them. The $90 carer payment is woefully inadequate for the level of care that I provide. I have no wish to profit from my beloved son but the payment should reflect the level of care and expense required. Tax deduction would be a way of reducing the burden on the working family. I also firmly believe that when a profoundly disabled medically fail young person has been cared for at home for over 20 years that carer deserves RESPECT not to be treated with the paternalistic, patronizing contempt that I face when I have the temerity to request help or to question woefully inadequate care provision in both respite and permanent care. I AM INCENSED THAT WE CURRENTLY ENJOY A HUGE FEDERAL SURPLUS - THAT MY SACRIFICE AND MY HUSBAND'S HARD WORK HAS CONTRIBUTED TO AND THAT I HAVE TO ENDURE SUCH STRESS, UNCERTAINTY AND DEGRADATION IN THE FORM OF BEGGING FOR HELP AND THE NECESSITY OF HAVING TO LAY BARE MY SOUL AND EXPOSE SUCH PERSONAL PAIN IN AN ATTEMPT TO ATTAIN AN APPROPRIATE LEVEL OF CARE FOR MY SON.

Catherine Murray