

Submission  
No 197

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

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Partially  
Confidential

**7 August 2018**

**Submission to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW**

**NSW Parliament**

To whom it may concern,

I am writing to you on behalf of my long-time friend Dave Young and his disabled son Alexander Young. I began sharing a house with them a couple of years ago when I relocated to NSW, with the intention of moving elsewhere when I was able to financially support myself again. I'm still here because of my concern for Dave's ailing health and wellbeing as a solo full-time carer.

Having had scant experience in the marginalised world of disability, my journey has been eye-opening, stressful and at times shocking to say the least, but has provided me with invaluable insight and deep empathy for all Australian families who care for a disabled loved-one. There's always an upside.

Alex is 26 years old, has cerebral palsy, autism and is wheelchair-bound. Dave is 64 years old and has been Alex's full-time carer since about 2010. He was recently diagnosed with a hernia after years of increasingly heavy lifting and dragging Alex (70kg) and his wheelchair up and down eight house-steps twice daily. Alex's invisible, wealthy mother lives about ten minutes away but has nothing to do with him apart from having him overnight once or twice a month. She uses work as an excuse and allegedly won't seek help for her mental and emotional issues because she fears losing her job (ironically) as a nurse in the disability sector. Extensive overseas travel is also one of her favourite past times.

My primary reason for this submission is the fact that Dave has been waiting for several years for a wheelchair access ramp to be built. His initial pre-NDIS submission came to an abrupt standstill possibly because it coincided with the chaotic changeover to the new system. Well over a year ago, post NDIS implementation, a new ramp submission was lodged. The plans were council approved earlier this year but the hefty (outrageously inflated) price tag seems to be an issue. Dave and Alex's 'ramp file' also appears to be caught up in a game of high level 'pass the too-hard-basket'.

Dave reported his hernia diagnosis to the NDIS Gosford office in mid July 2018 and was assured his case would be escalated. Apart from a follow-up telephone message informing him that his case is progressing, nothing has happened. Meanwhile, Dave's health is declining from the daily stresses on both a physical, mental and emotional level. His pending hernia surgery is an obvious issue because carers would not be permitted to drag Alex and his wheelchair up and down the stairs while Dave is in hospital and at home in recovery. The mother clearly can't cope with Alex and his challenging behaviours so it would be a risk for him to stay with her.

The ramp will make an enormous difference to the quality of life for both Dave and Alex. It would enable carers to assist Dave, give Alex the chance to transition to a more independent existence and allow Dave to reclaim some of his life and personal needs, which have been severely neglected due to his selfless commitment to Alex. Unfortunately, extreme selflessness often culminates in health problems on all levels, which is where things are at right now.

In my view, disability is clearly an exploited industry while the NDIS and State Government disability sector hierarchy appear to be devoid of compassion and decision-making skills. On the other hand, I have nothing but respect and gratitude for the NDIS case workers and occupational therapists who have assisted Dave and Alex with addressing other needs such as new wheelchairs.

Also worth mentioning is that therapeutic massage is not recognised as a legitimate NDIS claim, whilst physiotherapy is. This is ignorant, outdated and disappointing because the benefits of massage are widely documented. Alex's two recent massage sessions left him feeling deeply relaxed and uncharacteristically calm. He also enjoyed a peaceful sleep, which meant Dave enjoyed a peaceful sleep - a rare occurrence when living with disability. Sleep deprivation is a leading cause of Alzheimer's Disease, so let's hope the NDIS assigns someone to research effective therapies to ensure massage by an accredited practitioner is added to its list of approved therapies.

Ongoing, adequate disability funding by the NDIS and all state governments to ensure access to advocacy, representation and information simply shouldn't be an issue. As far as I am concerned, all politicians and public servants who play a role in the disability sector, from administrative to cabinet level, should be required to undergo mandatory work experience in a disability care centre - even for one day. There is nothing like firsthand experience of the harsh realities associated with dealing with disability on a daily basis. Given the blatant waste of taxpayer funds on irrelevant projects such as sports stadiums to appease blinkered boys' clubs, it's not a big ask to ensure adequate funds are made readily available for our most vulnerable people to ensure they receive quality support for the rest of their lives without having to wait three years for a decision to be made.

My first visit to a disability care centre was so disturbing that it prompted me to draft an article about the lack of ethics within the neo-natal life-saving medical technology industry. Seeing lifeless adults strapped to mobile flatbeds, unable to speak or move, was heartbreaking.

Millions of dollars are spent in Australian hospitals to keep seriously afflicted babies alive who have extreme health issues and limited signs of life. Medical technology is a wonderful thing but specialists don't have to go home with the babies they are saving and begin the challenging, often isolated journey that follows.

TV news reports love to tell us about 'courageous fights' to keep premature babies alive while parents of disabled adults quietly wish that Australian hospitals would provide enlightened counselling for parents during the trauma-ridden journey that begins when a seriously afflicted baby is born.

For example, at birth, Alex was given a 10% chance of survival and specialists were divided about 'fighting' to keep him alive. \$125,000 later, Alex survived. It was a traumatic time for both parents who previously lost a premature baby girl who died soon after birth. Following Alex's birth, his mother failed to seek the psychological help she needed and it was all downhill from there.

I have also learned that marriage breakdowns are commonplace following the birth of a disabled child, a high percentage of mothers desert their disabled kids once they turn 18 and family support often falls by the wayside from the outset or over time. Perhaps facts such as these need to be gently communicated to traumatised parents of lifeless babies in neo natal wards to assist them in their decision to allow medical technology to play God. They could even be encouraged to visit a disability centre or a family home to see the life that awaits them. Educating expectant mothers about the crucial role self-care plays during pregnancy would also be a valuable investment.

In closing, western world medical technology and mindsets fight to keep seriously afflicted babies alive instead of humanely letting nature take its course. But that's another inquiry.

Sincerely,

**Linda Summer**