

Committee:

Tabled Document

Inquiry: 2018-19 Budget estimates

Date: 1 June 2018

Witness: Senator Brown

Organisation: \_\_\_\_\_

8<sup>th</sup> March 2018

Dear NDIS and Minister for Disability Services,

We are writing to express our extreme disappointment and loss of hope in the NDIS. Last week, our son, Tim transitioned onto NDIS. While we are grateful for the funding packages for equipment that he so desperately needs, as well as some specialist services, we were absolutely devastated that he was only allocated 70 hours a week support services out of the 336 hours/week urgently requested.

As of 31<sup>st</sup> March 2018, we, his parents can no longer continue to provide physical/hands-on care for Tim (we currently provide in excess of 150 hours/week each and are aged 70 and nearly 72). We simply cannot keep going. Our hope is gone, our minds and bodies are giving up on us – we have waited so long and are now so devastated. We had lived in hope that finally with the NDIS Tim would be able to get the amount of support services he must have to be able to stay alive and remain living in his family home. We have only survived on prayer and adrenalin for years – we are now about to collapse, and are sick and tired of fighting and waiting

The NDIS schedule states that services that are reasonable and necessary will be provided and makes reference to care being provided 24/7 for those who need it. In our case, this has not occurred. 70 hours a week goes virtually nowhere towards covering the 336 hours/week care Tim requires (two workers to be present at all times due to his challenging behaviours, seizures and degree of physical and cognitive incapacity). We had been expecting at least 168 hours/week in the initial plan (so as to provide one support worker 24 hours a day) and then an increase to two workers at all times once assessments are completed.

Without care 24 hours a day, during the daytime: Tim will have to be seated (fully restrained) in his wheelchair most of the day being unfed, dehydrated, screaming in pain, wallowing in urine and faeces, getting cold/hot, becoming highly distressed and fearful with no-one to comfort him, unable to access any entertainment/activities, etc, and be at extremely high risk of dying due to falling out/trying to escape the confinement of his chair, sliding down in his chair and strangling on his harnesses, or having unattended seizures causing him to die from asphyxiation; and at night-time he would have to lie restrained in bed and freeze if his blankets fall off, get bed sores from not being turned, be at risk of suffocating when he rolls under his pillows, thrash and scream all night in pain, lay in urine and faeces and coughed up blood (brought on by severe reflux from bleeding ulcers – up to 600ml of blood at a time) or die from his unattended seizures. This is preventable cruelty at its worst.

Who will take the responsibility for the pain and suffering and death of a young man eligible to receive reasonable and necessary care from the NDIS and yet has been let down by the extreme failings of the system? Certainly not us as his parents –due to our deteriorating health and extreme tiredness, our bodies and minds will not allow us to continue providing hands-on physical care, so

the responsibility for his physical care now has fallen on the government (as of 1<sup>st</sup> January 2018 when Tim became eligible for the NDIS).

So our only course of action (so that we can survive and due to the inability of any other family members taking on the caring role) is: as of 31<sup>st</sup> March we will no longer be able to provide physical care for Tim. We require NDIS to provide in-home care 24 hours a day, 7 days a week with two support workers at all times (including one active and one mostly inactive during night shifts). We propose that NDIS create an immediate three month plan that allocates 336 high intensity care hours /week to Tim starting as of 31<sup>st</sup> March which will fill the gap from when we stop providing physical care for Tim until all the necessary assessments are completed (medical evidence is already available) which will provide NDIS with the evidence they need to lock in permanent in-home 24 hours/day x 7 days a week x 2 workers care for Tim for the duration of his life.

Additionally, we will notify the media of this situation on 30<sup>th</sup> March if NDIS has not met Tim's needs.

If you are worried about the cost of this proposal (we estimate approximately \$200,000 for the 3 months gap period) – consider the cost of investigations into the neglect and ultimately the death of a young man and coronial inquiries, etc. Consider the pain, suffering, stress and fear Tim (who has endured so much pain and suffering all his life) will have endured.

In the past week, since we were notified of the appalling lack of support hours provided to Tim, his challenging behaviours and pain levels have increased dramatically – his is feeling even more vulnerable, being aware that his parents are not coping and that the news of such an incredible shortfall of funding has had massive emotional toll on his mother (to the point she has had suicidal thoughts) and father (to the point of him reaching physical collapse last week due to stress induced shaking, etc). Tim also has given up hope and has become highly stressed.

As of 31<sup>st</sup> March we will be exercising our human rights according to Article 24 of the Universal Declaration of Human Rights: "Everyone has the right to rest and leisure, including reasonable limitations of working hours and periodic holidays . . ." For the past 31 years, we have had very little (if any) access to this human right –for example in Oct/Nov 2016, Peter went 13 days and nights with a total of only two hours sleep as he was caring for Tim non-stop whilst Beverley had a broken leg – he eventually collapsed and required an ambulance – since then, Peter is lucky to get 2-3 nights broken sleep each week and provides care to Tim every other night as well as most of the day for most days each week, and Beverley only half sleeps due to needing to be alert to respond to and assist with Tim's needs 7 nights a week, as well as provide care throughout the day every day as well as prepare meals, clean, do the laundry, etc. We can give you many more examples, but the point is – we now require the government meet our human rights obligations by allowing us to stop having the carer role for Tim, and thus start to have a rest after the approximately 250,000 hours of high level care we have each provided Tim in his lifetime (the average fulltime working person will have only worked around 50,000 hours during that period) – a saving to the government of approximately \$25 million. It is well and truly time the government fulfilled its obligations toward Tim and us.

And another issue is the length of time it is taking to be able to access vital equipment for Tim (such as a motorised wheelchair, hoist and bed). Since Tim became eligible for the NDIS on 1<sup>st</sup> January 2018, he can no longer access the Tasmanian Community Equipment Scheme, which means he cannot have his current wheelchair fixed (it has now reached a dangerous point as the brakes do not

work), and he cannot access a tilt nursing home style bed that doctors recommended he urgently obtain just a few days prior to 1<sup>st</sup> January. Also, he needs a better wheelchair with harnesses that will provide proper posture support. He has now been waiting more than 2 months for these urgent pieces of equipment and will have to continue to wait until he can access assessments by OT's etc, and then order the equipment, etc – potentially still weeks, if not months away. Why should he have to suffer extreme pain and deteriorating posture (and associated deteriorating health) because there is a gap between Community Equipment Scheme service provision and NDIS service provision – surely commonsense would prevail and he would be able to access something in the meantime?

We are now asking these questions: a) how was the conclusion reached of only providing 70 hours a week support services in his first plan – what was this based on? And b) will you now accept full responsibility for Tim's physical care and provide him with 336 hours a week in-home care for 3 months whilst the assessments are being done and the continuation of this care for the duration of his life? c) can you please provide Tim with immediate access to the equipment he urgently needs? and d) is there any cap on the amount of NDIS support funding an individual can receive, or is the criteria simply what is reasonable and necessary?

By 31<sup>st</sup> March, we will have finished revising Tim's Support Plan – nothing less than implementing this plan will be acceptable.

Sincerely,

Peter and Beverley Rubenach

NB. None of these questions have been answered or even acknowledged

x Due to Tim's rapid deterioration, we of course have remained steadfast by his side giving our love and care constantly.

Balm 121 – Tim's special, personal word from God.

"God guards you from every evil, He guards your very life. He guards you when you leave and when you return. He guards you now, He guards you always"