

Submission
No 99

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

Name: Mr John Burchell
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Partially
Confidential

Colin's NDIS Battle

Colin was born, he had a feeding problem. At 2 month of age he was sent for some tests. On the 02 July 1985 they killed him. (See Attached) By bringing him back to life Colin was left with major brain damage which has left him solely reliant on other people for all his day to day living. Colin cannot walk he is reliant on a wheel chair which he needs to be hoisted too and from. Colin is in nappies as a bowl prolapse prevents his use of a commode. Colin cannot verbally communicate and has no signing understanding. He is reliant on a CPAP machine to keep him alive at night as his oxygen levels fall to a critical level. Colin lives in purpose built high dependency accommodation with 4 other people this is now run by The House With No Steps organisation. In spite of all this Colin is one of the most happy, placid people you could wish to meet.

Due to this brain damage and the ageing process Colin is in need of special dietary needs. He requires thickened fluid drinks or he would aspirate and possibly drown. Due to developing dysphagia he also requires food supplements as he is only able to cope with 2 cupfuls of meals a day, plus a few Wheatbix for breakfast.

Prior to the NDIS Colin paid 75% of his pension to the NSW Government for his board and lodging which covered all his food and drink requirements. Now the NDIS has revised his plan and have not allowed any funding for his special needs food and drink, without which he will die. Their excuse is that it is a NSW Health issue. NSW Health refute this saying it is up to the NDIS. The politicians are also passing the buck and pointing the finger at each other.

Meanwhile Colin will still pay 75% of his pension to have board and lodging plus having to fund the special dietary needs. He will be bankrupt in a couple of months. Then we his parents will have to find the funding, possibly selling our house to keep Colin alive. Or would the politicians prefer we give him normal food and speed his demise.

Colin has this year had his funding for his day placement cut, he will now only be able to attend for 9 months. This will mean Colin will be left at his residence for 3 months with very little stimulation and probably a great decline in his mental and physical well-being.

Last year Colin received funding to go out into the community on a one on one basis with a carer. Just prior to this Colin was in a very poor metal state and was being considered for medication for depression. It became very apparent to all that he became his old happy self once the outings therapy had been applied. This year Colin's funding for these outing has been cut but even worse he has been allowed no funding for any transport. It really begs the question who could make such a decision. Colin has so little to look forward to in life the NDIS would put Scrooge to shame.

In dealing with the NDIS we are lead into a false sense of security at the planning meeting in the belief that Colin's needs are being met, only some weeks later to be told his funding is no where near that required. This ongoing battle is extremely stressing and as pensioners who have such a vulnerable child we should not have to battle each year to ensure the health and well-being of our child.

In the hope of someone helping.

Yours John & Dianne Burchell