

Submission
No 48

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

Name: Mrs Karen Cartwright

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Our two sons both with a rare deteriorating condition called Batten Disease have been affected by the NDIS. Firstly the transport costs are insufficient making it difficult for our boys to access daily programs/activities hence limiting their needs to be included within our community . Another aspect has been the insufficient staffing across numerous agencies for home care, day programs and home accommodation, there is definitely not enough funding for these agencies to operate effectively to provide the client with their necessary needs. Our youngest son has just been terminated from his day program due to insufficient staff, we have been given four weeks!!!! this is disgraceful how they can do this to our family. We are a family in urgent crisis and have no help from the government. Before the NDIS I could contact the Commonwealth Respite Service and they could help when we were in crisis to provide some well deserved respite before drastic situations occurred. We have been trying to find some short term accomodation for our son/s so we put in a review with the NDIS and when we received the review we were down \$30000!!! so now our budget for care has reached its capacity my husband has to find a job asap so we can survive but I need him to help me in the home with our two sons aged 19 & 22years ..they are big boys both in wheelchairs, need hoisting, have extreme behavioural disorders, worsening seizures & the onset of dementia has started. We want to give our boys the best possible life they can have as their life span is shortened. Overall we have found the NDIS to be alot more work, yes you do have choice and control but theres not that much choice for necessary day programs, respite and necessary accommodation. The government needs to have a good look over this...& support those in desperate need here in Australia.