

Submission
No 239

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

Name: Mrs Melinda Adderley

Date Received: 9 August 2018

INQUIRY INTO THE IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICE PROVIDERS IN NEW SOUTH WALES

Submission of Melinda Adderley and Paul Adderley (parents of a young man with server disabilities, complex health and comorbidities)

We are making this submission as parents of a young disabled man with complex health and comorbidities.

Our son is at Summer Hill Group Homes, he is a profoundly disabled young man who has a complex medical and health history. He has microcephaly and developmental delay, he is 25 but his developmental age is under six months, he communicates happiness through vocalisation and laughing, he communicates distress and pain through crying, screaming, and hitting himself. Our son can hear he enjoys loud sounds, lots of noise and music. Our son also has cortical visual impairment, he has brittle bones where the calcium leaches from his bones and deposits in his kidneys subsequently he has ongoing kidney problem which if not managed properly can create ongoing infections. He has a floppy valve in his heart. His pain management is managed by a slow release patch, regular Panadol and oral morphine when his pain breaks through. Throughout his life he has had multiple hospitalisations.

Until the age of 18 our son accessed respite in the respite unit at Summer Hill group homes, this was particularly valuable when he had fractures and was unable to attend school, this was invaluable as it allowed my husband and I to continue working.

Since moving permanently into Summer Hill Group homes at the age of 18 our son has had no fractures, his kidney infections have been markedly reduced and his quality of life has improved significantly. This is because of the level and ratio of nursing care he receives and the hygiene standards of the facility.

We have found the ADAC services transition very stressful. We were told that there would be no change then we are told our permanent Allies Health staff will be leaving and transferring to the Benevolent Society. Therefore, the promise that nothing would change was broken. Within three months there was no Benevolent Society staff working at Summer Hill group homes it was an absolute disaster. The parents and the NUM's had to work together to pool money and hire appropriate staff.

Throughout the process we have felt like there was a philosophy of railroading as well as divide and conquer. To develop the 'Principal to Guide the Selection of a Non-Government Provider for the Summer Hill Centre' a woman for PWC came in to facilitate the development of the process it was expected that we would develop it in the couple of hours allocated. When it became blatantly obvious that this was not achievable she complained about the time we were taking trying to get it right. It gave the impression that getting the guidelines right was not really that important. When the NGO's came to pitch to the families the guidelines handed out were not the ones we had developed.

NGO's pitching to take over Summer Hill group homes have said that they expect money from the government through health to support the Summer Hill residents, yet they cannot explain how much it will be or the formula used to calculate it. This is very worrying as we know that our son's NDIS package does not cover the cost of his care. We do not know what happens if the NGO takes over and they cannot afford the costs there appears to be no back up plan. If the parents decide the NGO is not capable of providing quality care we can't remove them for two years.

Some of the worrying comments from the NGO's that pitched to take over Summer Hill Group Homes are as follows:

- When asking to guarantee the cost of shared medical expenses – items not covered by NDIS could come out of the share household living expenses or negotiated funding from NSW Health
- A tendering NGO said they had limited information on the way Summer Hill Centre is run on a day to day basis (yet they feel they are able to keep the same model, without knowing how it is to be funded)
- When asked about FAC's responsibilities and how they would work with FAC's we were told to speak to FAC's (yet they have previously taken over ADAC facilities, which FAC's still owns)

The problem with people like our son is, if you get the quality of care wrong it can seriously impact on their health and if the level of care decreases it can be a matter of life and death. While our son may be on palliative care we do not want him to die, changes in the level of services provided could put his life at risk. We have no confidence that the funding needed to support our son, and the others who live with him, will be available. We feel that the NGO's will be in a position where they have no choice but to cut the quality of the service.

At the end of the day there is no guarantee how the care for our son or the other residences of the Summer Hill Centre will be funded. Our son lives in this model because of both his health and disability, the NDIS funds his disability component but not the medical. If was only dealing with a disability he would not be living at the Summer Hill Centre he would be in a facility for people with disabilities or living at home with his family. Our son's life is depended on living in a hospital type model and there appears to be no guarantee of covering the cost.