

Submission
No 233

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

Name: Name suppressed

Date Received: 9 August 2018

Partially
Confidential

Our daughter is a very complex case with a diagnosis 27 years ago of Tuberous Sclerosis with Autistic Tendencies, Epilepsy, and major behavioural issues. As the years went by she was admitted to emergency respite for 6 week spells as her behaviours worsened. Something no parent wants to do is to surrender your child, you feel very guilty, but we also have two other children. Finally full time emergency accommodation was received and she lived in the small rural town for 4.5yrs under the ADHC funding. Unfortunately there was a change in management at this service provider and no behavioural support was sourced (not that it wasn't available) blaming it on quote "your daughter needs specialised care and we can no longer support her" unquote. I have since received an apology from the board of this particular service provider.

Our daughter had to be placed in yet another emergency accommodation for 4 months in a small country town till her new residence in a bigger rural centre was available. This has caused enormous amounts of stress and anxiety to our daughter. The service provider did alterations to the house to make it suitable for 2 people to live in the house. Unfortunately for our daughter, no compatibility study was done and there has been issues with her house mate, and due to our daughter having behavioural issues, where she was blamed yet again. We were told by the service provider that if our daughter can't live with her house mate we may have to find alternate accommodation outside of their services or she will have to live there on her own which she would not be able to afford the rent.

As we all know, or should know if you were in the disability sector that no two disabilities are the same and people that work in supported accommodation need to be trained in each person's complexities. Since living with this particular service provider our daughter has had a fractured skull resulting in 9 stitches due to SIB which is caused by anxiety, 2 x impacted bowels where she was admitted to hospital, major weight gain, staff inconsistencies and staff being trained. The accommodation service provider finds working with our daughter incredibly difficult. Though they tell us that their staff are well trained, they are not. They do not seek our input, and we have no choice and control. There was an alleged incident involving a staff member and our daughter. The staff member was moved from working with our daughter who has got no idea why and is left to grieve another loss. The 'investigation' has been ongoing since early this year. We are not allowed to know anything, or to ask for information about the incident. I have spoken to the Ombudsman with no result, they have no power. We have no choice or control about who works with our daughter or who her key worker is. Staff are unable to implement behaviour support programs provided to them or understand the importance of them. I feel so frustrated and worried for our daughter. We know her complexities make working with her challenging. They have not offered us face to face meetings to sort out the problems. If we voice our concerns, they show us the door. They have already threatened us with this.

After our NDIS plan meeting in November and receiving our plan in January we find it very difficult as parents to not have been called back by our Local Area Coordinator to actually explain the package.

In your plan meeting you request to have specific people that have dealt with your child for all the years through ADHC which we know now is called the Benevolent

Society. Since January I have been fighting to receive my CHOICE of support coordinator. Which is all you hear in the campaign's regarding the NDIS.....CHOICE AND CONTROL!!!!!! I have had to write a letter to the CEO of the Benevolent Society to get what I want for my daughter. She has support coordination funding. Why would we go with someone else that doesn't know our daughter where it states CHOICE AND CONTROL for the supports you need. I have spoken to the NDIS on numerous occasions to find the information where it states that you can't have the support coordinator of your choice.

Apparently, The Benevolent Society is the best of the best and were given the Government agency contract. We feel that we are being bullied by the Senior Management of the Benevolent Society into using another benevolent office. Again why would we spend our daughter's dollars on someone getting to know her when we already have someone?

Things have always been difficult for our daughter and us as her family. When the government, ADHC existed we had all the supports we needed, with choice and control. What matters most we felt sure that our daughter would be supported and always have a place to live.

We don't feel that now. We are given funds through the NDIS but no security that no matter what, our daughter will be safe and looked after.

<https://www.youtube.com/watch?v=C8ft13q23r8&feature=youtu.be>