

Our Family's personal journey with our son who is now severely physically, mentally and intellectually disabled.

Our son was severely intellectually disabled from birth. He attended a special needs school in Penrith area of NSW until December 2011. In April 2011 he had some dental work then we noticed a change in his behaviour and his health we desperately tried to get respite care for our son initially but were told by ADHC – now known as Human Services in NSW that as he was “not known to them” they could not help us even though in the past they had provided us with speech therapy and occupational therapy and to try the commonwealth respite services. They could not offer us any help. This continued for a number of months trying to get help from them until June 2011 when our son was admitted to Nepean Hospital for Neuroleptic Malignant Syndrome as a result of a medication he was on. This left our son paralysed down one side of his body. He went from walking to being in a wheelchair, feeding himself independently to be totally dependent on people to do everything for him. We found that staff at the hospital had to be educated on how to deal with a person with special need and we found ourselves at the hospital after work each day and all day on our weekends. Hospital staff are not trained to deal with people with a disability. So often our son was referred to as a naughty boy – not a person with a disability

Initially we were told he would make a full recovery. By October 2011 we were told that there was nothing more medically the hospital would do for our son and he would be going home. From this point on we were placed under enormous pressure for him to leave the hospital as they needed the bed but at a hospital meeting they were told with us that it could take 2 to 3yrs for ADHC to find him accommodation and made the point that this would be anywhere in the state of NSW depending on where the vacancy existed on what they called their immediate needs list.

2 separate applications to go on the immediate need list were lost between our Penrith case manager and senior management at the Parramatta office who determine if an application should make it onto their immediate need list. We only finally made it onto the list when a The Penrith Disability Resource centre and the State Member for Penrith Mr Stuart Ayres became involved. No one should have to go through the stress of this whilst they have an ill person to care for in hospital.

Nepean/Blue Mountains health did not want to bear the cost of accommodating our son for this period so their solution was to put pressure on us the family. We battled the pressure to keep him at Nepean Hospital but on the 21<sup>st</sup> March 2013 he was transferred to Springwood Hospital a further 30 minutes away. Again we spent every available minute with our son after work and on weekends. As before like Nepean Hospital there were staff who did not know how to handle a person with a disability and we had a number of incidents that occurred at the hospital where other patients decided that to keep him quiet when we were not there to hit him and sort him out. We also had an incident where a staff member decided to take it upon herself to punish him because she could not handle him one particular day so she shut him in his room with the light off and no TV and to keep him up in his wheelchair. When I arrived at 5.30pm he was exhausted as he normally goes back to bed about 3 to 3.30pm but he could not tell her that his toe was sore due to an ingrown toenail that had been reported to staff several days earlier

Up until April 2014 our son had only been considered for one of their houses at Terry Hills but this house clients were all in their sixties and our son at this stage was 21yrs and a long way from Penrith but we were told we have no choice as there are no vacancies and we had waited so long for this

one choice to come up. When they took him to view the house the incline of the ramp was so steep that only one member of staff could push him up it to the house. Due to this he was eliminated from being considered for the house.

At the end of April 2014 after so many meetings and threats from the social worker for Nepean/Blue Mountains health we were informed that if a place was not found by the 30<sup>th</sup> June 2014 they would seek guardianship and have him placed in a nursing home,. These constant threats of putting him in a nursing home had been made to us since October 2012 at Nepean Hospital. No family should be treated like this. We were caught between a health department who did not want the expense and a bed being taken up by our son and ADHC that had no places available.

During this time Denise Roberts from Penrith Disability Resource Services with the State Local Member for Penrith Stuart Ayres lobbied NSW Health and Minister for Disability Services.

ADHC are winding back services due to the NDIS. We were told at the beginning of 2014 ADHC were not building any new group home and were in fact closing places. There was one in Wollongong.

In April 2014 we did not know what to do and a petition was started on change.org.au was started to lobby the state Premier Mike Baird and John Ajaka. This petition was never presented due to the 30<sup>th</sup> June 2014 deadline to find accommodation.

The system failed us again with ADHC. We were informed by our case manager that a previous application from them had failed for us to apply for the YPIRAC program (NSW Younger People in Residential Aged Care which is part of ADHC could not get it right if we qualified. Right at the last minute in a second application was lodged and this time we did have a meeting with the staff of the YPIRAC program and were informed that he would qualify as he did have a neurological change after the age of 18 but they could not promise when a place would come up as there were over 200 people needing urgent accommodation. Luckily for us a place came up quite quickly and he moved into the Northcott house under the YPIRAC program on the 2<sup>nd</sup> of July 2014. 2 days after the 30<sup>th</sup> June deadline and even then we had to plead with the health department not to go ahead with their threat to take out temporary guardianship.

No one should go through any of this we had to take out guardianship due to the constant threats from the hospitals. Where the justice for people with a disability....where is there no discrimination for people with a disability. People with a severe disability should have the right to find suitable accommodation near their family. Our son is in a group home 40minutes from us. This means if we want to bring him home it is a very expensive taxi fare. We are lucky a lot of families have their family members a lot further away from them. But what happens when we get old and can no longer drive to visit him. The way the system is we know he will never get a place closer to us so many people in the disability sector say where they end up is where they stay don't forget ADHC words to us our son could end up anywhere in the state and then how long does it take to find accommodation. Took us 2 yrs. with a lot of lobbying both in the media and politicians. We were a very private family who would never ask for help but when you have a severely disabled person who you are responsible for you have to go way out of your comfort zone to get them just a place to stay. 2 years ago you would never have found me sending this letter but I feel so strongly of the injustice and battle my family has gone through and the damage it has caused to my husband and my health that I need to speak out for other families that do not have the strength to follow through and get

the help they so desperately need. There needs to be a smoother system whether it is state by state or as a nationally system. With a national system everywhere in Australia it should be equal. I think it is definitely harder to find accommodation in western Sydney compared to the more affluent northern suburbs where there are more non-government organisations operating in the area.

From my experience as a parent I would be concerned about any number provided to the enquiry considering our family made 2 applications to go on the immediate need list with ADHC and it took our local State member of parliament to look into our application and why it went missing and considering the Penrith office's own word were none of the applications they have submitted over the last 2 years had been approved to go onto the immediate needs list. What happens to anyone who does not make it to ADHC's "immediate needs list where are these people counted? My understanding is anyone under the age of 60 is considered a young person to be going into a nursing home. That is a lot of people.

There are no medical staff who specialise in disability like psychologists, even GPs do not know how to care for people with severe disabilities who cannot communicate. We spent 3 months trying to find out what was wrong with our son before he was admitted to hospital. In all fields of medical expertise there should be ones specialising in disabilities and ADHC or their equivalent should have a list of these practitioners that parents can be referred to. The average specialist does not know how to communicate with these people. It could save lives and people like my son could get the specialist care they need much earlier and diagnosis earlier.

From my experience with ADHC you just get pushed around going absolutely nowhere with no definite plan or procedure of what the process is when you ask them and then after much shuffling of your file you fall off their system and have to start from the very beginning so there is no true record of how long you are on any waiting list.

The new accommodation provided by Younger People in Residential Aged Care Program is fantastic I cannot complain about the accommodation provided for our son but people do not know about it and that included the staff within ADHC. In the 2 years we were waiting why it took until the last few weeks for ADHC to realise that we did qualify for this. It is a good program but no one knows about it so it cannot be effective...Sounds like the program you have when you don't have a program. We know the house took people in from March 2014 our son was only the second person to move in in July and only in November did it become full. Why did it take so long to fill when there are so many people waiting for accommodation except they are not told about it?

The down side of the NDIS is the ADHC looked after the most severely disabled people in the community. Yes it costs more to look after these people so it is not so attractive to non-government Organisations and I think these NGOs will be able to pick and choose which clients they like and will choose the easiest people to care for and the more profoundly disabled will always be at the bottom of waiting lists. This is a big concern. Also a lot of people who have been with ADHC are leaving the industry. Their knowledge of working with the more profoundly disabled will be lost. From my experience The NGOs seem to have less exposure to working with people who have more severe disabilities and as a parent of one such person this is a big concern