

Penny Callaghan

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To whom it may concern,

I have two sons with autism spectrum disorder. My ten year old, Will, also has an intellectual disability and he attends Diamond Valley SDS. This school to date has best served his sensory and emotional needs. He started school at Bulleen Heights then moved to Northern School for Autism (NSA) and completed a term at Mansfield Statewide Autism Services (MASS) which he received a once off funding allocation from DHHS. This term placement occurred during a very difficult time: I was going through a marriage breakdown, Will wasn't sleeping, he would not feed himself or sit at the dinner table and he continually defecated in his room making a huge, unhygienic mess. Will was not only very unhappy at NSA but he was also shuffled around between my rental property, time with his dad and time at Wiluna Court Briar Hill respite house (DHHS).

Will's placement at MASS has been a huge success but the battle to get him there was an extremely difficult one. I had been trying very hard to acquire the funding for him for close to twelve months. I was despairing of my own sanity and ability to care for a child who could not care for his own needs in a very basic way. I advised staff at DHHS that I planned to relinquish Will as I could no longer cope with the meltdowns, fecal mess and lack of sleep. Miraculously the funding appeared through undisclosed channels at DHHS. Will completed his term in Mansfield during Term three in 2014, but NSA did not provide any funding or assistance for this placement.

To summarise very briefly Will's term at MASS provided him and myself with the tools for Will to be more self-reliant, a few examples to illustrate: he could occupy himself quietly if he could not sleep; feed himself with a spoon or fork; to stay seated at the table during meals and to walk beside me when near roads or public spaces. After his stay at MASS, Will completed term four at NSA in 2014 but it was clear to me that they were not meeting his needs (emotional and sensory regulation) nor my goals for Will (independent living skills).

Will commenced the 2015 school year at Diamond Valley SDS (his fourth school in four years of schooling). Will is very happy there, he swims at the specially designed pool two days a week and rides the school's horses which help with his sensory, social and emotional development. Will is currently only medicated for sleep (melatonin) and for constipation (osmolax). We see the paediatrician every six months; the continence paediatrician every six months and the continence nurse rings approximately once a month. I am on the phone to DHHS at least once a week regarding supports and respite. Help during the school holidays has been scarce until this month March 2016 when Will was finally granted an ISP but it is too late now to organise any school holiday programs for the Easter break.

One of the most difficult adjustments that we have needed to make is the closure of Wiluna Court respite house in Briar Hill. DHHS opened a 'purpose built' house in Rosanna which looks like a hospital ward. This house is located 17 kilometres from my rental home in Kangaroo Ground and approximately 9 kilometres from the school. Since the new DHHS house opened respite access for Will involved trying to arrange at my expense for Will to be transported to the house from school by a volunteer organisation called Link Community Transport. Previously transport from the school to the house when it was located in Briar Hill was conducted by the school Mees buses. This option was no longer available when the house was built outside of the school zone. On the 14th September 2015 at 3:30pm I received a call from Ann Harper at Link stating that they were unable

to transport Will to the respite house from school (no volunteer drivers were available apparently). At the time I was meeting my younger son's bus at St Helena arriving from NSA. This designated bus stop for Robin (my other autistic son) is 3.5kms from Will's school and 12 kilometres from the house in Rosanna.

After writing yet another letter of complaint, the education department permitted the school's Mees buses to drive outside the school zone from the start of this school year (2016). When the Mees bus service delivered Will to Wiluna court in Briar Hill it was a smooth transition from home to school to respite house. Communication between the bus driver and chaperone and the school, me the parent/Carer provided the necessary relief I need in knowing that Will has been transported safely to an environment that seems to meet his needs adequately. Unfortunately the new house in Rosanna is a two hour trip for Will twice a day. Will was allocated a spot in the house for two nights a week but this has now been reduced to one night due to the huge distance between my house and the respite house. I've made this decision for a number of reasons but primarily the 20km drive to the house does eat into the respite hours significantly.

I am constantly on the phone to schools, psychologists, DHHS case workers, behavioural consultants from EPIC (education programs for infants and children at rmit), doctors, continence nurses, agencies for respite or personal care, Mees Buses, Link Community Transport, Prospect Rd Respite House. This is just the bare bones of my existence with one autistic child. I have not the space nor time to begin Robin's story here though his is equally worth telling as I'm terrified for his safety due to his tendency to run across busy roads when his impulses get the better of him.

Yours sincerely,

Penny Callaghan