

Committee Secretary of the Inquiry

I am a carer of a 17 year old boy and a 3 year old boy both with uncontrolled epilepsy, both of which their daily needs are many.

My 17 year old boy had a febrile convulsion in February of 1993 and was fine until August of 1993 when he had two seizures and was put on medication after a few tests were done and then we had to go to the Prince of Wales Children's Hospital at Randwick in Sydney for an MRI's and EEG and to see a Paediatrician Neurologist for possible answers to no avail. He has had constant epileptic seizures over the years since. He has had a couple of MRI's since and also had a Telemetry in 1995 which showed he had epileptic activity on both sides of the brain and he can only be controlled medically.

My 17 year old was diagnosed with Polymorphous Epilepsy (Epilepsy that keeps changing) at Tumbatin Developmental Clinic in December of 1994.

My 17 year old has a moderate to severe intellectual disability and severe uncontrolled epilepsy.

He has also been on various epileptic medications since 1993 and over his 17 years, some of which he has reacted to and had to be swapped due to the reaction and others were not controlling his epilepsy.

He has been under various Doctors locally as many have come and gone over the years. He has been under Paediatricians over the years locally and from away that have travelled to Cobar and we had also had to travel to Dubbo to a Paediatrician once for an assessment for Centrelink purposes.

He has been under four different Community Support Workers locally and from away over his 17 years. He is currently under a Community Support Worker that is based at Bourke but travels and has an office at Cobar.

He has been under various teams from Dubbo over the 17 years for Early Intervention for Speech, Occupational Therapy, Physiotherapy, Hearing and Behaviour and Assessments. He did have Speech and Occupational Therapy locally for a few years and from Sydney for Speech Therapy and we also travelled down to Sydney for weekly blocks of Speech Therapy. He was under a Better Life Consultant for 12 months from Dubbo and a Paediatrician who travelled to Cobar for a couple of years. Speech Therapy now again from Dubbo and is on a waiting list for Occupational Therapy from Bourke and on a waiting list for Physiotherapy from Dubbo due to fine and gross motor needs.

He has always had a Teacher's aide over his schooling years for various hours and at times this has been a hurdle at times due to misunderstandings or change in the way the school implemented the way they applied the I.O. support needs or not enough funding for schools and for the number of Students with high support needs mainly in his primary school years.

He has been under a few Student counsellors over his schooling years.

In his early Primary School years we had misunderstandings due to his epilepsy and his actions sometimes due to his epilepsy and other times situations due to his inappropriate actions to other children and people and I was told to talk to him right from wrong instead of it being dealt with on the spot and other times people not knowing how to communicate with him and at other times people not knowing of his condition have not realised that he has had a seizure or two and he has reacted and they have misunderstood why.

My 17 year old is currently on three epileptic medications and on 1 that is a mild valium or diazepam, iron tablet and one for nausea due to him being periodically sick. He is in Year 11 and has staggered lessons and is totally dependent on me for his medications and taking him to and from school daily and to appointments when required and when he is at home. He has teacher aides daily and his work is modified to his ability and understanding level.

He has constant Doctor appointments for checkups, when sick, prescriptions and for any tests including blood levels of medications and centrelink purposes and any other medical needs, when we can get into a Doctor as we are having a Doctor crisis where we live. We have Specialists appointments every 6 months in Sydney and hopefully next year in Dubbo.

He needs constant supervision when sick and when having his seizures and around his three other siblings at times.

He is on a Disability Pension.

He will need help for employment in the next couple of years and the employer will also need help.

Who knows what the future will hold for him.

My 17 year old and his younger sibling are currently under a Genetics Team at Newcastle to see if there is a Genetic link between them and they are under a Geneticist at Sydney Children's Hospital and tests are still being carried out and they are both still currently under the Paediatrician Neurologist from 1993 at Sydney Children's Hospital.

My 3 year old toddler has Mild Global Developmental Delay, mild hypotonia (low tone), Speech Delay, fine and gross motor skills delay and epilepsy.

He is also on medication for his epilepsy and is totally dependent on me due to all his illness and is not toilet trained and only started to walk last August and implementation of his Speech and Occupational Therapy programs.

He sees a Paediatrician that comes to Cobar once a month.

He has weekly sessions under REACH Early Intervention for ¾ of an hour from a REACH Facilitator for Speech and Occupational Therapy.

He sees an Occupational Therapist that comes from Nyngan 2 -4 times a term sometimes less and she does assessments and provides goals and programs for the REACH Facilitator, me and the Preschool to work with him to improve his skills.

He sees a Speech Pathologist that comes from Sydney once every three months for an assessment and to provide Speech programs for the REACH facilitator me and the Preschool to help him with his speech.

He was having Physiotherapy last year until the physiotherapist went on Maternity Leave and is currently on another waiting list for physiotherapy which was applied for last October and he is still waiting and he is currently also on a waiting list for Speech Therapy and Occupational Therapy so he can be under the one team instead of under a couple who work with REACH Early Intervention and we are still waiting to hear.

He goes to Preschool one day a week on Fridays for socialisation with other children and adults and to learn more skills.

He is on a Health Care Card.

He has also been very ill with his epilepsy during the months of April and May this year and we were flown to Dubbo on the ninth of May due to him going into Status Epilepticus and a Doctor shortage.

I also have two other children, one boy 15 years old and a girl 5 years old who also had a Phonological Delay with her Speech and had to have Speech Therapy through REACH Early Intervention for a couple of years.

I do get Host Family Respite during the week but also depends on the wellness of the children and of my mother-in-law.

My husband is a shift worker in the mill at one of the local mines so the majority of looking after the children and the daily household duties, shopping and paying the bills are my responsibility.

He has constant Doctor appointments for checkups, when sick, blood levels of medication, centrelink purposes and any other medical needs.

Terms of Reference

The Role and Contribution of Carers in society is very necessary as there is a wide range of individual needs for people with a wide range of Medical Disabilities and Disabilities of all ages.

As a mother in my early 40's of four children and a carer of two of my children with Disabilities I am committed to the daily needs of all four of my children.

The barriers to socialisation is limited due to the health of my children and weekly visits to Early Intervention sessions of my 3 year old and the staggered lessons of my 17 year old and medical visits ranging from weekly to monthly visits with Medical Doctors locally either at the Medical Centre or a locum up at the hospital and every six months away with Medical Professionals for both children.

Due to my circumstances at the moment for both boys and over the next few years even for my youngest son, and even after the next few years I might not be able to apply or obtain employment due to their uncontrolled epilepsy.

I might be needed at any time of the night or day and the flexibility of hours and no suitable after school care for their needs.

I could be up all night and not to be able to concentrate at work and a strong need for someone to be home when the children are home.

My 17 year old is home at varied times during school hours and varies from week to week depending on his lessons and getting to and from school.

School Transport is not an option. Support network for carers i.e. options for after school care and supported network for my 17 year old to have and to find work out in the community.

I am unable to even do extra study at TAFE for employment options due to their uncontrolled epilepsy. Even the cost of the TAFE courses are unreal and are too much out of pocket to even think do a TAFE Course or Courses.

The contribution of carers should not be underestimated and could be made much easier through less complicated paper work when applying for assistance and duplication of every two years to prove that they have a Disability to Centerlink.

To supply long supported accommodation for young adults within the local Area.

Someone to help navigate through the various and confusing options face to face, not a voice on the other end of a phone, email or fax machine.

Processing for transition from school and out into the working community to start early in the final year of schooling to allow effective transition from school to work and on to self care reliance.

Joan