

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

19th January, 2014

Dear Committee Members,

**Re: Prevalence of different types of speech, language and communication disorders
and speech pathology services in Australia.**

My name is [REDACTED] and I am the mother of a beautiful seven year old boy named [REDACTED]. I would like to share some of my family's experiences trying to get support for [REDACTED] who has a severe receptive and expressive communication disorder.

In 2007 we were blessed with the arrival of [REDACTED]. He was welcomed into our family and was a very easy little baby to care for – who slept well, fed well and loved to be cuddled and be fussed over. He was a very smiley little fellow and in that first year was known by others for his infectious giggle and love of attention. He was curious and adventurous and as a family we loved every moment with him.

As time went on, it became very apparent that [REDACTED] wasn't progressing normally. Despite engaging in lots of "conversations" there was rarely a recognisable word. He also seemed to not understand much of what we were saying and had difficulty

following simple instructions. [REDACTED] also had difficulty responding to any verbal interaction which didn't also use lots of other queues such as pointing or offering a visual to assist with understanding. An example of this would be offering [REDACTED] a drink. I would need to show him a cup and gesture drinking from it. A simple question of "would you like some juice or milk?" was not understood until he was shown both containers which he learnt quickly to point to and to choose the one he wanted. I'm sure you could imagine how frustrating this was for him.

Our beautiful boy went from the happiest little baby to a very frustrated little boy who would scream, kick, hit, pinch and at times bite. As he had a minimal ability to understand, trying to calm him or to help him learn the skills to be able to adapt and be more age appropriate was near impossible. He also didn't have an ability to express what he was feeling. The words he needed were missing. Such as being able to say he felt sad and angry or to convey a message such as I want, I need or stop it.

So here we were with this child who had minimal ability to understand us or for the most part, for us to understand him. It was obvious to raise our [REDACTED] we were going to need a lot of help and that is what we sought.

[REDACTED] was two years old when we approached Queensland Health about accessing speech therapy. He was placed on a waiting list and we were warned that the wait at that time was about nine months. At that stage we were told over and over how early intervention was crucial for our child so we began to place his name on various waiting lists for speech therapists all over Townsville in North Queensland. At that time, the private therapists had huge waiting lists. Every conversation we had highlighted the need for early intervention. It felt as though salt was being rubbed into our wounds as despite being so desperate for help, it was unavailable either via the public or private systems.

While waiting to move to the top of the list, we did the best we could. We had also been blessed with baby number three in that time. Finally we received news from Queensland Health that a placement was available for [REDACTED] for speech therapy. We were so relieved and also amazed that the public health system was able to accept [REDACTED] before the private. The Speech Language Pathologist (SLP) was exceptional. After six sessions she was replaced due to staff changes and at [REDACTED] seventh session the new SLP did another assessment and warned us that she wasn't sure if we would be offered more than eight sessions. During our eighth session we were informed that it would be the last one. This was conducted by yet another new SLP who spent the session tidying up paperwork on [REDACTED] The

explanation for ending the sessions was that there was approximately another 120 children on the waiting list so [REDACTED] needed to go back onto the list to be reassessed in the future for more therapy. I asked if the SLP thought he needed therapy and she replied that he definitely did but I should be happy with what I'd been given and it really wasn't her problem. After following up with her supervisor and only by escalating it as far up the chain of command as I could, including a complaint to Queensland Health and our local MP, I was offered access into a program called "More Than Words" which was for parents of children with autism and social communication disorders. The program was very worthwhile however there was minimal work conducted with the children as the aim was on teaching the parents to manage their child's complex communication issues. It also meant that my husband had to take a lot of time off work over the months that the program ran as [REDACTED] was not allowed to attend the sessions.

While attending the "More Than Words" program I became aware of the world of how to manipulate a child's diagnosis in order to attract funding. Many of the parents who attended the session had children who had a diagnosis such as Global Developmental Delay or Specific Language Impairment – neither of which attracted funding through the Better Start program. Parents shared their personal journeys and what they were doing to ensure that their child would get an autism diagnosis so they could receive funding for support and services. It wasn't because they wanted to scam the system – they were just so desperate for help. One lady even told how her husband and her planned to separate as they felt she would be able to access better supports for her child if she was a single parent. Each of these families had a child with a severe communication problem as their primary issue.

After this program was complete, I pushed for more help as [REDACTED] had still only ever received eight therapy sessions. He was referred to another Queensland Health team to be assessed. After his assessment we received a report which highlighted a need for Speech Therapy, Occupational Therapy, Physiotherapy and the possible involvement of a psychologist. I was beginning to feel very hopeful that help was on its way however things fell in a heap once more when they found out that [REDACTED] had been accepted into an Early Childhood Development Program (ECDP) at a state school. They explained that they wouldn't double up on services with Education Queensland however after speaking to his teachers at ECDP, it was highlighted the only therapy offered by Education Queensland was as a consultation service to assist the teachers. [REDACTED] needed much more than this.

As time went on [REDACTED] problems only escalated. He became very anxious and frustrated; he was totally unable to communicate the simplest of messages. We

became more and more isolated as when we did go out we were met with the most dreadful comments. Please take a moment to really think about how you would feel if other people, watching your child grunting, squealing and being generally inappropriate for their age, said to you, “if he was mine, I’d kill myself.” If this was an isolated comment it wouldn’t have felt so bad however he was regularly called a retard, a savage, and an animal. We were always asked what was wrong with him and often it was suggested that we should put him in an institution. Our day to day lives were fairly chaotic to say the least and help was scarce.

It was early in 2011 that things finally come to a peak. Our house sustained substantial damage during Cyclone Yasi and while still cleaning up the mess we were devastated to learn that my sister had died. It was horrific. Our lives were turned upside down and all this while trying to manage a child with a severe disability and two other children. That year we did receive some wonderful assistance for my son in terms of mornings in a child care centre. We also managed to access Occupational Therapy and Speech Therapy with Disability Services Queensland. We were made aware that help from DSQ would stop once he turned six however the quality of the therapy received was very good and really did make a huge difference.

Like magic though, while cleaning out my sisters belongings I discovered a name of a child neurologist and phone number which my sister had sourced off her transplant surgeon for [REDACTED]. We travelled to Brisbane mid-year to see the doctor who was a breath of fresh air. He explained in detail that [REDACTED] had a severe Speech Language Disorder. He said that children like [REDACTED] often have autistic traits, sensory issues, major behavioural challenges, delays in all developmental domains, problems with gross and fine motor skills and most worrying was that this would have a major impact on his ability to learn. He explained that children like [REDACTED] are often diagnosed as having Autism or Intellectual Impairment when the primary issue really is a Speech and Language Disorder. We asked if there was any place that he knew of, anywhere, that could help our son. Then our new journey began. He suggested, The Glenleighden School at Fig Tree Pocket which specialises in helping children with Primary Language Disorder.

We approached with caution the thought that maybe this was going to be the lifeline we had been so desperately looking for. We had looked into education options in Townsville and our application to private Catholic schools was declined despite meeting their highest criteria for application. Our best option in Townsville was a public sector school however they lacked good fencing, resources and I was horrified when it was suggested by one school that the special needs children at the

school were put in bright vests at playtime so staff could monitor them more easily. It was also suggested that I might have to volunteer teacher aide time in other classrooms to free up aide time for my son. I was told that although the staff would do their best to accommodate [REDACTED] that it might be necessary for him to only attend school for half days depending on human resources as he was a child with very high support needs. We went through the process of applying to The Glenleighden School and gathered the information required. We will never forget when the phone rang and the beautiful voice on the other end said that he was accepted into the school for 2012.

Quickly we put our new house on the market and sold it for peanuts to just offload it in the bid to start our new life in Brisbane. We said goodbye to our family and friends, took a deep breath and hoped that our decision was the right one.

[REDACTED] started school like any other little one on their first day. He seemed nervous and excited. From the first week we felt reassured that The Glenleighden School was the best choice for our child. [REDACTED] progress is exceptionally slow however there is progress.

Despite The Glenleighden School being the best option for [REDACTED] it all comes at a cost. School fee's come in at over \$10,000 a year and additional private therapy has also been required. Most years' we spend approximately \$20,000 on helping [REDACTED] We also lost about \$135,000 between the sale and purchase of our house in Townsville to our new home in Brisbane. Financially we are starting over however we also feel fortunate that we were able to make the move in the first place and despite many sacrifices to keep [REDACTED] at the school, we are privileged that we can still manage to pay the fees to keep him there.

When reflecting on [REDACTED] I often think of a conversation which I had last year with a cousin who had just come back from a wonderful holiday to China. He was sharing stories with us about his adventures and started to tell us about his attempts to communicate with a few of the locals. I remember him saying, "I gave up trying to talk to them. What's the use? They can't understand me and I couldn't understand them". He proceeded to explain that it was less work to just not bother.

My cousin is a lovely man and he didn't realise that what he said was so important for me to hear. People don't talk to the [REDACTED] of the world as they might not understand or respond appropriately. It is hard work for others to try to have a conversation with my son and it is exhausting for [REDACTED] to constantly have to work out what people are saying, what it all means and what he should try to say or do. It

causes frustration and inconvenience for the person who can speak and understand the language. I can't imagine for a moment what it must be like for [REDACTED] to be constantly at the receiving end of that frustration and attitude.

I also often reflect that [REDACTED] lives in Australia. His native language is English and he has a limited ability to use his native language and to understand it. He can't move to another country as he doesn't know their language either. I often feel powerless knowing that so little support is offered for people like [REDACTED] by their own country, which by all accounts is a wealthy, stable country with wonderful people as its citizens. It makes me question why is he so invisible and why isn't government taking notice and offering a voice to the children of this country which literally have none. They are so vulnerable and need strong, passionate representation which is ongoing and reflects an urgent need for help.

For my family, we are hopeful that [REDACTED] will be able to access support through the NDIS once it is rolled out in Queensland however we have no idea what that support might look like in real terms or if he will be eligible.

I have so many concerns and spend much of my time thinking about what more I should be doing and what could I do differently to help [REDACTED] I worry about the future. I worry about dying and not having anyone to care for [REDACTED] My 78 year old mother who lives with us worries that she will die as she is such an important part of our support network. We worry that I might never be able to find a job which fits in perfectly around [REDACTED] needs therefore our family will never get ahead and will always struggle. We think about [REDACTED] statistical risk of ending up in prison or with a severe mental health issue. We worry that he will always have difficulty learning and that this will impact his ability to work. It bothers us terribly that he will be at risk of living in poverty and of homelessness if we weren't around. It worries us that he lacks social skills, is so vulnerable and at risk of being hurt by those in our community who seek opportunities to do so. My eldest son has voiced concerns that he knows he will have to look after [REDACTED] when we die. My three year old daughter already has to manage a brother with behaviour which absorbs so much of her parent's attention which should also be hers to have. [REDACTED] communication disability impacts all of us.

Over the years the impact of raising a child with a severe communication disorder has been immense. There is definitely a huge amount of time involved in driving to and from appointments, time in waiting rooms, time at therapy sessions and doctor's appointments. There is also the time it takes to follow up with all the homework which is given from a variety of therapists. The impact it has had on our

relationships is also huge. We have drifted slowly away from many friends and family who have little understanding or patience for [REDACTED] differences. Those that have remained in our lives are treasured. Our own family unit is constantly under pressure to manage. This includes coping with [REDACTED] challenging behaviour and our responses to this, having to constantly adapt to fit in with [REDACTED] schedule, having a very tight family budget which has [REDACTED] needs as the priority, additional stress on our marriage and on ensuring each family member feels important, especially our other children. There is nothing in our life which has not been affected by having a child with a communication disability.

As much as there are significant challenges to raising [REDACTED] we also have moments of immense joy. The first time he was able to tell us his first name was an amazing day. He was five years old. Last year, he began to consistently be able to recognise his own name when it was written and by the end of the year he was writing his name so that others could understand it. They might sound like simple achievements but for [REDACTED] they are huge and offer glimpses of hope and a sense of achievement.

In terms of the quality of speech therapy which [REDACTED] has received over the years, I would say it has been of a good standard. Queensland Health had some quality therapists however the big ugly system got in the way of them being able to do what was needed for [REDACTED] When [REDACTED] received therapy from Disability Services Queensland he was fortunate to have an exceptional SLP and OT. Privately, we have seen a few SLP's however the cost is considerable and continues to dictate the types of help we are able to offer [REDACTED] The Glenleighden School has an emphasis on delivering a language based program so we remain hopeful that he will continue to have some gains from the help he receives at school.

[REDACTED] is only seven years old and over those years I've come to the realisation that disability is big business in this country. We are constantly told that we need to do more for [REDACTED] and are left to decipher which services might have a true benefit. People in [REDACTED] life currently include – school speech therapist, school occupational therapist, school music therapist, school physiotherapist, horse riding for the disabled through school, teachers, private occupational therapist, private psychologist and a private paediatrician. We have been encouraged to also consult a dietician, yoga for relaxation, buy a variety of iPad apps, have private physiotherapy and consult a naturopath – to name a few. Of course the business continues down all sorts of paths with so many non-traditional options being on offer. All come at a hefty price without any money back guarantee if the service doesn't meet expectation of its promised outcome.

Questions and comments from therapists when trying to push their latest and greatest treatment can really offer a new layer of confusion, shame and guilt to an already complex situation. An issue which we have found perplexing is how having a communication disability doesn't seem to be enough and we have been constantly pushed to get more and more and more assessments which cost up to \$600 each. It's distressing and financially difficult. Another issue we have found difficult is that all therapists come with their own personal opinions with a push towards their belief. It can sometimes feel as though [REDACTED] is not receiving a program tailored to his needs and is having to endure what others perceive is needed.

One of the most peculiar aspects of visiting so many health, allied health and education professionals is the constant undertones that maybe [REDACTED] could be so much better if we were better parents. I can't remember the push to engage in parenting classes with my oldest child and definitely haven't had it suggested for my youngest. With [REDACTED] we have had countless brochures on the Triple P parenting program given to us. Please note, I'm not criticising the worth of such programs and am always open to self improvement however it was so glaringly obvious to us as parents that [REDACTED] many challenges were not because of anything we had done or not done and thankfully my husband and I had each other to offer such reassurances. I'd encourage any professional working with children to approach families without judgement and to ask both the person with a disability and their advocates the basic question, "what types of support and services do you need?"

As realists, my family is aware that the road ahead for us will be very bumpy, with lots of twists and turns. My husband [REDACTED] and I are like any regular parents – we absolutely believe in the potential of our children. Despite [REDACTED] many differences, our hopes and dreams for him are so similar to those for our other children – to be happy, self confident, find a good job and to be a valuable, included member of the community.

I would encourage you to take a genuine and ongoing interest in children and adults with communication disorders. I would also encourage you to take notice and act on research which will no doubt be presented to you outlining research such as statistical evidence of alarmingly high rates of juvenile offenders with communication problems.

Thank you for the opportunity to make a submission to the inquiry. Please contact me if I can be of further assistance.

Yours sincerely,