1. My name is [redacted] My son [redacted] who turns 8 in February suffers from verbal dyspraxia (developmental apraxia of speech). [redacted] father [redacted] and I are both lawyers and he has an older sister [redacted] We live on the Gold Coast.

2. [redacted] had an uneventful birth at full term, and I did not notice any unusual developmental signs until he attempted to talk.

3. [redacted] started babbling and making sounds quite early, but he didn't develop speech that was comprehensible. The vowel sounds in the middle of the word were there, but often the consonant at the beginning and/or end was missing. There were many consonant sounds [redacted] could not make at all. The "s", "f" and "th" sounds immediately spring to mind.

4. Our immediate family sometimes got the gist of what [redacted] was saying if it was in context, but nobody else could understand him. He developed his own sign language, which he used to ensure I responded promptly to his needs. He would make sipping noises and hold a pretend cup to his mouth, when he wanted a drink or point to his open mouth when he was hungry. He was also a skillful mime and used mime as an adjunct to his speech.

5. I thought, being a boy, he was just a late starter and his speech would "clear up" with time. He was and is a bright, happy, affectionate, funny and loveable boy at home.

6. At the age of 3, I enrolled [redacted] at our local C and K kindergarten for 2 mornings a week to assist in his socialization prior to school. His kindergarten teacher mentioned that his speech was behind the other kids and recommended a speech pathologist. [redacted] coped at kindy, as he was mainly painting and playing in the sandpit and was not there for long periods of time.

7. After we secured an appointment with the recommended Speech Pathologist, I then drove [redacted] to her office (an hour round trip) weekly to consult with her. Her advice was that she would have him talking like everybody else by Prep. She did not diagnose his condition and he made no noticeable progress over the year. His behavior was extremely difficult to manage at speech therapy. At the time I thought he was being naughty and uncooperative, but I now realize that the things asked of him were so very hard that he just couldn't cope. The experience meant that [redacted] diagnosis and his treatment was critically delayed by a year.

8. Around this time [redacted] frustration levels began to rise and his behavior became more difficult. Because of how he sounded, some people treated him like he was mentally retarded. Kids made unkind comments about him, within earshot, when we were out. They told him he "spoke like a baby" at the park and rejected his attempts to play when they couldn't understand him. His sister's school friends would ask what was wrong with him. He still could not even say yes (sounded like "when") or no (sounded like "doe"). He could not say Mum, Dad or his sister [redacted] name (sounded like "Uee"). Associated symptoms of his dyspraxia included extreme sensitivity to loud noise and poor physical co-ordination.

9. Just before his fourth Birthday, I did some internet searches and found the Let's Talk Developmental Hub in Brisbane. My husband and I drove to Brisbane and over 2 days, a speech pathologist, OT and physiotherapist tested him. His test results revealed that although his core language skills (semantics, morphology, syntax and auditory memory) were in the 91st percentile for his age, he presented significant difficulties being understood through connected speech and he made articulation errors that were significantly below age expectations. The speech pathologist noted difficulties in sequencing movements, typical of dyspraxic children. He was also found to have low tone and below average gross and fine motor skills (16th percentile). Despite his results, we were advised that he was not eligible for entry into the Glenleighden School (which specializes in children with primary language disorders), because his core language skills were too high. His vocabulary was advanced but his speech was unintelligible. We were advised that this meant that the school would be unable to obtain funding for him under the criteria for speech and language disability. I found this a bit depressing, as I considered that the early, intensive and specialist intervention that Glenleighden could have offered, would have really fast tracked [redacted] progress. We would have been prepared to move to Brisbane for [redacted] to access all of his treatment in one place.

10. Instead we were left to our own devices to find appropriate therapists in our area and pay for his treatment. This was a wee bit daunting. We had researched and knew that intensive therapy at an early age could make all the difference to children such as [redacted] He was already nearly 4. I could not find any support or advice for families of dyspraxic children on the Gold Coast.

11. Around this time we also arranged to have [redacted] hearing tested at the Neurosensory Unit and consulted with a leading local Pediatrician. [redacted] hearing was found to be normal and his word recognition excellent. The pediatrician diagnosed [redacted] as having developmental speech and language disorder (ICD: 315.3) and Controlling behaviour/apprehension/anxiety (V40.3). He was particularly

unhelpful and advised me to enroll [redacted] in a programme at the local Special School. I didn't take [redacted] back to him for any follow up sessions.

12. We were lucky enough to be offered a place for [redacted] at All Saints Anglican School, a private school on the Gold Coast, which has an excellent learning support structure. He began in kindergarten (which he repeated) and is now just starting year 2.

13. The school reviewed his test results and told me they thought [redacted] had potential. He commenced speech therapy with Speech Pathologist [redacted] [redacted] who consulted with him at school. Within 2 weeks [redacted] advised me that [redacted] had verbal dyspraxia. [redacted] and I decided to pay for [redacted] to have as much early intervention as possible. [redacted] was kind enough to see [redacted] twice a week for his first two years of schooling. This was not always easy, because of her busy (to overloaded) caseload. We actually would have preferred an additional session, but it was just not possible. [redacted] also consulted weekly with an occupational therapist and psychiatrist. He attended an early movement class at our local gymnasium on the weekend to help with his gross motor skills.

14. I have attended all of [redacted] therapy (speech, OT, psychology) to enable me to practice with him every day at home. I have needed to be available to drive him to appointments and meet with teachers, counsellors and learning support staff at school (sometimes at short notice). As a result, I did not return to work. The financial effect was not insubstantial but we saw no other option. I guess societal and tax revenue losses have also resulted from my exclusion from the workforce.

15. [redacted] worked very hard on his speech. Fortunately, his strong personality assisted him. It was very frustrating and repetitive for him but after 6 months with [redacted] we began to notice some improvement. He took one step forward and 2 back for the next couple of years and improvement was slow and gradual. [redacted] has had to learn to "rewire" his brain to make sounds. [redacted] also worked with [redacted] on his literacy skills, as children with verbal dyspraxia are at high risk in this area.

16. [redacted] developed some significant behavioral difficulties at school, which emerged in Prep. He was anxious about other students judging him as being sub-standard and tended to become aggressive when he perceived that he was threatened. He started to "do the runner" when things got tough in the classroom. Just imagine what it would be like if you could effectively formulate thoughts but were unable to communicate them because you didn't have the motor planning skills to produce words. That is the source of the anxiety which necessarily accompanies this organic condition and adds a layer of psychological disability to it.

17. I took [redacted] to an educational psychologist recommended by the school, for help with these problems and he has improved somewhat.

18. [redacted] attended speech therapy once a week in Prep and year one and his intelligibility has now improved to a level where he now only has residual errors and is comprehensible. He has graduated from Speech Therapy!

19. [redacted] continues with his OT, but I envisage that he will have completed this by the end of the year. I think the psychological imprint of verbal dyspraxia will linger for longer.

20. [redacted] has been provided with teacher's aide time at school, to assist his teacher to manage his special needs in the classroom. He has an Individual Learning Plan designed to overcome his anxiety and gaps in learning emanating from his history of dyspraxia. The school is unable to access any government funding for this, because [redacted] does not qualify under any of the existing disability categories. We are very fortunate that the school offers this level of support without access to funding. Most schools wouldn't be in a position to do so.

21. We have self funded all of [redacted] treatment and testing over the past 5 years. Although I have not added up our expenses, they are substantial. I have spent countless hours with [redacted] attending appointments and working with him on his speech, motor skills and early literacy. Medicare did fund a proportion of [redacted] consultations with Psychiatrists and Psychologists.

22. [redacted] year 1 report card showed that he was either meeting or exceeding the year level standard academically… even in oral presentations. [redacted] and I now expect that [redacted] will lead a full life and will have the opportunity to work in a career of his choice and have normal relationships.

23. Without early intervention, we doubt this future would have been open to [redacted] His speech impediment was such that he would have been unemployable and his relationships would have been severely impaired. Because he is so bright, I think his frustration levels and anger would only have increased as he got older, leading to who knows what trouble.

24. [redacted] and I have been able to help [redacted] because we are well educated and in a financial position to fund his private education, testing, therapy and survive on one income. This is the main reason [redacted] has made the progress he has. Not all children with dyspraxia have these resources available to them and it is these children who society should be looking after.

25. [redacted] has also been lucky in that we found the right Speech Pathologist who had the knowledge and experience to help him. [redacted] was able to establish a strong bond with [redacted] and understood that his initial uncooperative behavior stemmed from extreme frustration. I believe that it was this relationship upon which his gains in therapy were built. We can't thank [redacted] enough and hate to think what life would have been like without her. It is hard even to obtain an appointment to see a Speech Pathologist. It is even harder to find one with expertise if your child suffers from verbal dyspraxia.

26. Speech is critical to our ability to prosper as human beings. It is beyond me, why the government does not direct more resources to speech therapy. Even on a purely economic basis, I would have thought that it would be more economic to fund intensive speech therapy for a child for three or four years, than to pay unemployment/disability benefits to the same child for 50 years. Or worse still, to fund their incarceration. Kids like [redacted] have the potential to contribute to society, if we only invest in their early development.

27. [redacted] and I have already put our money where our mouth is and have received good results for our child. I think the government should do the same for dyspraxic kids whose parents are not so well off. We are astonished that children just like [redacted] but from families which cannot afford the necessary intensive treatment or the time of parents who cannot afford to stop work, can often not access any treatment except for 5 partially funded sessions per year. From our hands on experience this level of treatment is too little and the amount on offer was less than half the cost of a half hour session of Speech Pathology. We didn't bother applying because the actual cost of getting our GP to complete the extensive paperwork to qualify made it hardly worthwhile. The therapy treatment for verbal dyspraxia only works with persistent repetition so 5 sessions a year would be next to useless for a dyspraxic child. [redacted] sometimes had more sessions than this per month. He effectively had ten times this level of treatment in a year.

28. Society needs to address problems including access to advice and information for families, the number of appropriately trained speech pathologists, specialised training for speech pathologists in treating conditions like verbal dyspraxia, and funding for families and schools. The aim should be to enable the provision of the same level of support as is made available, for example, for children with autism and physical disabilities. The school funding model for children with disabilities like [redacted] is unduly restrictive and deeply flawed. Australia's commitment to children with speech and language disabilities (who do not carry also an IQ deficit) falls well below standards in other developed countries. Our experience shows that this is a disability which is readily treatable with proper therapy and support but that the responsibility for treatment lies almost

exclusively with the family. Therefore, the economic and attitudinal disposition of the child's family is the primary determinant of outcome. What other disability is so neglected?

29. How would you get by if you were unable to move your mouth automatically to produce speech?

Thank you for considering my submission.

[redacted]
3 February 2014