

My 4 year old son [REDACTED], has a severe expressive language delay, moderate receptive language delay, and has been diagnosed with Childhood Apraxia of Speech, and Verbal Dyspraxia.

At 4 years of age, he has terrible trouble speaking even single words, and cannot say his own name, or his brother and sisters name. He calls his brother [REDACTED] (Meh), and his sister [REDACTED] (Wah). Most of the sounds that he makes for words cannot be understood by me, without context or other clues, let alone by other children and his kindergarten teachers next year.

When [REDACTED] was 2, he started seeing a private speech therapist, after being on a waiting list for a few months. At this stage he had only one word, and most of his communication was via pointing and an "eh" noise, or dragging me to whatever it was he wanted. We started to use some basic sign language, and also PECS (picture communication cards) which alleviated some of [REDACTED] frustration, and enabled him to ask for some basic needs. After almost a year, [REDACTED] therapist could no longer see us on our therapy day. We were then put on a waiting list for an experienced therapist, who was available on the same days as we were.

After waiting a couple of months, in early 2013, we decided to try a different speech therapist that was available immediately. The search for the right speech therapist is in itself a major project. There is no register that can tell you who specialises in what types of therapies, it is really a guessing game. After about 20 weekly sessions with our local therapist, it was decided that we should focus on alternative forms of communication, due to [REDACTED] being uncooperative in therapy, and his lack of verbal progress.

We tried a few different apps, some hard to configure, some just didn't fit [REDACTED] needs, and after spending over \$100 and countless weeks of trialling and configuring, I found that Yooralla offered a grant for assisted communication devices. We applied for an app called Proloquo2go, and although I would have spent at least a full day getting the information for the application, it was worth it. This was \$250 that I just could not find myself, especially when you cannot "try" these apps before you purchase them. We are still in the training stages of using this app, and [REDACTED] will take it to kindergarten when he starts at the end of January.

As [REDACTED] has not been diagnosed with any of the conditions that are eligible for FACSIA/Better Start funding, I am left to cover all therapy costs. I am thankful that there is support for children with other specific diagnosis (autism, angelman syndrome to name a couple)., however I have seen some children of a much higher functioning than [REDACTED] (they can talk, actively participate in kinder, but may have a tendency to be aggressive to others or have a diminished sense of safety) and they are eligible for an aide for Kindergarten. Children with critical communication needs should also be eligible.

[REDACTED] kindergarten has 28 children enrolled for next year, and only 2 teachers. I have tried all avenues, many meetings with various people, to try to get [REDACTED] access to an aide, but he does not qualify under the current KISS guidelines. There will be no-one available to assist [REDACTED] to use his new form of communication, and I fear that [REDACTED] will be isolated by his communication difficulties, and this will definitely hamper his learning and diminish his confidence. He needs someone to act as an interpreter, as I have seen firsthand how children will come to play with [REDACTED], and when he does not reciprocate in conversation, or they do not understand what he is saying, they will just walk off and find someone else to play with. This is absolutely heartbreaking to watch.

This heartbreak is a daily part of life, to watch [REDACTED] struggle to find a word, then to not be understood once he has made such a big effort to get it out. To watch him play on his own, with only his soft toys Mickey and Baa, who never ask him questions or look at him strange for the way he speaks. How isolating it must feel to not be able to communicate, to not be able to say your own name when someone asks.... I have not been able to send [REDACTED] to crèche, even though I have needed a break as much as anyone, because he is very dependent on me, and it probably feels as if I am the only person in the world that may be able to understand him. I had no idea before [REDACTED] came along, how debilitating the inability to produce speech could be.

At the moment [REDACTED] is under the guidance of a speech therapist through our early intervention program, but this is just guidance, not therapy. As [REDACTED] has made little verbal progress, and can be "temperamental" I can't be certain whether he would gain anything from typical therapy at this stage, but if cost was not a factor, I would be doing it on the chance that it would help even in a small way.

I would like to see severe communication problems be treated as just as important as any physical disability. I would like to see children whose parents can't afford speech therapy, not be at a disadvantage to the wealthy children. Also, before a child is put on a waiting list for speech therapy, I think they should immediately be assessed (under a doctor's referral/government funded platform). I would like to see the FACSIA/Better Start funding extended to include severe communication disorders, and if a child cannot communicate on their own, I believe that they should have access to an aide for kindergarten, as they need to be able to develop social skills and learn, just as any other children do.

I thank-you for the opportunity to have this input into your inquiry.

Kind regards,