

## ██████████ ██████████ 9 years old, Apraxia of Speech

### **Brief history**

Our son ██████████ has a speech disorder known as Apraxia of speech. Apraxia of speech occurs when a person tries to communicate but the muscles required for speech – mouth, tongue, lips, jaw – can't form the right sounds or sequence the sounds together to make words.

Comprehension can be within the normal range and there is nothing wrong with the muscles, however for some unknown reason the message sent from the brain gets scrambled and speech becomes very difficult. The only treatment is regular, intensive and expensive speech therapy. This condition however although very much a disability is not currently recognised as one.

██████████ is 9 years old and has a twin brother and an older sister.

He was diagnosed in 2007 when he was 3 years old and began attending speech therapy at the Westmead Hospital in Sydney.

In 2011 after very little progress and changing speech therapists about 4 times in search of one that understood Apraxia, we put ██████████ in a speech research study at Sydney University. We attended the University 4 days a week for 3 weeks and then at various other times for assessment. During this time we learnt about Max's House in Brisbane. A family experiencing the same frustrations as us sent speech therapists to America to undergo intensive specialised training in the United States, currently the world leader in research into apraxia of speech and in developing therapies to treat the condition and began a clinic in Brisbane.

We spent the following school holidays in Brisbane attending this clinic daily and at the end of 2011 we sold our Sydney home and moved to Brisbane. We have been attending Max's House twice a week for over two years.

### **Cost**

For a half hour session we pay \$85. This is a monthly cost of \$680, approximately \$8000 a year. We receive \$500 back from our health fund and \$250 from Medicare on a care plan for which we need doctor's visits and paperwork. This is a total of \$750 a year in assistance from an outlay of approximately \$8000.

### **Impact for ██████████**

- Distinctly different and not always understandable speech.
- Frustration in not being understood.
- Difficulty in schoolwork particularly reading, writing and spelling.
- Difficulty communicating with teachers.
- Difficulty communicating with fellow peers limits his capacity to make friends and he is also an easy target for bullies.
- Feelings of isolation and inferiority, low self-esteem.
- Changing states, schools and communities.
- Constant speech therapy since the age of 3.
- Travelling 40 minutes each way to speech twice a week after school is time consuming and limits the ability to do afterschool sport or other activities.

**Impact on family**

- Selling the family home, changing states, schools, jobs and community.
- A reduction in income with job changes.
- An increase in speech therapy costs.
- Travelling 40 minutes each way to speech twice a week after school is time consuming and limits the ability to be able to participate in afterschool sport or other activities.

Apraxia of Speech needs to be recognised as a disability and assistance provided to sufferers and their families.