From: Emma Bird
To: Committee, EEC (SEN)
Subject: Re: Current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support
Date: Wednesday, 5 August 2015 7:04:17 PM

To: Committee Secretary
Senate Education and Employment Committees
PO Box 6100
Parliament House
Canberra ACT 2600

My son has a diagnosed chronic stutter (with a family history). When we first realised it was outside of the normal range of childhood stuttering (as most children go through stages where they may stutter during their language development) I sought advice about what I could do to help my child. Fortunately for me I have a few friends who are Speech Pathologists who offered advice on what to do next. We started seeing a private Speech Pathologist to assess his stutter and speech development and she confirmed that he did have a 'classic stutter' and that it was not within the normal parameters of language development, furthermore it he had been stuttering for more than six months, putting him into the 'chronic' range. Naturally we sought help and guidance from her to help our son with a program for stuttering developed in Sydney, called the Lidcombe Program. The Lidcombe program is a program that has been developed over 20 years and has lots of data and results to prove it's effectiveness. You can find some more information here for data, in depth information about the necessity of early intervention for stuttering and the effectiveness of the program http://sydney.edu.au/health-sciences/asrc/

Stuttering seems like an insignificant sort of diagnosis and we assume that it affects only speech. We have found, as with true/ classic stutterers that stuttering does not only affect one's ability to communicate fluently, but it also has big psychological effects. Our son was always a confident, happy, calm and very sociable child. Within six months of stuttering he became very shy, withdrawn, displayed anxiety, became quite introverted and, as a result of constantly struggling to get his message across he became extremely frustrated and angry. To see so much change to your child's persona is heartbreaking.

Weekly Speech Therapy does not come cheaply. We pay between $130-$180 a session/week! I have had to extend my special leave(as a Primary School Teacher) with no pay to support our son, and the financial implications of this on our family is huge.

We tried to get in to the Public system next, to take some of the financial burden off. When I first rang the North Lakes Health Precinct to inquire about how to get in, the lady I spoke to on the phone said we needed a GP referral. I got the referral, and rang back to get the details to get into their system. This next lady on the phone said that stuttering was not really seen as an issue at 3 years old, disregarded what I said and said that it was very low on the priority list for assistance. I asked if there was another way to try to get in more quickly and she said I should go through Child Health (Child Health and Development has since made contact with me about this matter and has been very polite and apologetic, but still they do not have the funding, nor expertise to help my child with the level of support that he needs).

We made an appointment with Child Health and after asking all of four one-word-response questions to my child, she declared that there was no stutter (once again after he said four words, his name, his age, etc)! She was reluctant to refer me on and implied that maybe the Speech Pathologist was taking me for a bit of a ride! I have never felt so insulted!

Only after I contacted Senators, Health Ministers (both State and Federal) and local members did someone contact me and offer to interview us to determine our eligibility for the public system.

We have now changed Speech Pathologists and drive to the South Side of Brisbane every week (from Caboolture) to get my son the support he so desperately needs for his best chance at low level stuttering/stuttering that is more manageable over his life span.

The ONLY support we are entitled to from the government is $250 a year, spread over five sessions (i.e. approximately $50 per speech session for 5 weeks)....that is something, but pitiful in helping families in this situation. A whole year of weekly Speech Pathology intervention at $135 a week is over $7000!

I have a close friend who also has a child who stutters, and also has a family history of stuttering. She had her appointment in the public system a few weeks ago and they told her they won't do anything until she is 4. She is almost 3, and has had a consistent stutter for almost a year now too. It breaks my heart to think that this child will now have barely any chance at all to reduce the severity of her stutter. With the correct intervention this child would therefore have better chances overall at succeeding academically, socially and eventually, in the workplace.

The current system is failing these children. There is not just a gap, but a large gaping hole and these poor little children (and families) are not able to access the support they need to help them. That is so unjust and goes against the equitable measures put in place in our health system.

I have also contacted Wyatt Roy's office and they have contacted relevant Federal Ministers who have also confirmed that there is not anything for these kids, but I feel they didn't have the understanding of the issue to know that it is not a short-term issue and implied that it is something that they will grow out of. I do acknowledge that some stuttering is normal in child development, but there is a vast difference between this and classic stuttering.

As I have outlined above, our journey through the Health System and to get a better understanding of stuttering has been a complex and arduous one. To know that these children and families are being pushed aside and that their very real concerns for their children's communication abilities is falling on deaf ears is an injustice. It goes against what we, in this Nation stand for, it is inequitable and unjust that these families go unsupported.

As a teacher, I know the expectations of the schooling environment, and I also know the limited support systems available to children once they are in the system. My fear is that parents are leaving these conditions until their child is of school age will be severely detrimental to the development of the child socially, emotionally and academically. Research clearly shows how this negatively effects children within school, into their adult life.

My child has an above average, if not an exceptional intelligence level. I am up to date with every immunisation and health check. I care for him and give him a good diet, I encourage his gross motor and fine motor skills, I read to him, I play with him, I take him to the library, I delight in his singing, his stories and it is an honour to watch him grow into a beautiful and unique human being. I am doing my job as a parent, and I love him deeply and meet his every need. It is the system that is failing my child and our family, it is the system that is not only failing my family, but many others with childhood language disorders. Failure to provide children with their right to intervention and services is robbing them of their fundamental rights, and depriving them of a multitude of lifelong outcomes. Our children are our future and we need to take the time to invest in them and to support them both before schooling starts and within the schooling system, the deserve the very best.

Time is of the essence for these children to get them the intervention services that they need, and a better start to life. Support from the government for a chronic condition like stuttering is severely limited and this has huge effects on the individual child emotionally and socially, without access to this essential health care these children are markedly disadvantaged and their lives will be significantly impacted as a result.

My Speech Pathologist has also given me the all clear to bring this issue to the relevant peoples attention because she has seen first hand what happens when people don't get intervention and when they are financially burdened from the private speech appointments. She has also told me that the current government has had formal appeals from the gurus of stuttering in Australia to address this issue and it has had no results.

It is encouraging to see some much needed discussion around this issue and I would be open to discussing it further via email or you can contact me on .

Warm Regards,

Emma Bird