# SUBMISSION BY AMANDA HANNA

## Background to our son's needs and lifestyle:

I have a 6 year old son, Luke, with Cerebral Palsy and a visual impairment. He needs assistance with all daily living requirements, has the usual problems associated with severe CP and also has anaphylaxis to milk, egg and nuts. We started Luke at school after a long fight with the DET who wanted to put him into an SSP even though he doesn't have an intellectual disability. Under the current system there was no way that he could attend the lovely school that his brother and sister attend as, although they have other children with disabilities there, they would have needed funding for Luke, and it is a private school. I feel this is wrong. Luke should have been able to go to school wherever we anted him to go, and especially with his older siblings. The disability unit he was placed into in the local public school was inadequate for his needs and he was not happy there. He cried all day and I had to keep him home in the end.

I am now not only Luke's mother and full-time carer, I am also his homeschool teacher. I purchase and modify, or create from scratch, all of his resources to cater not only for his physical disability but also his visual impairment and receive no financial assistance for this, even though I am saving the government money by homeschooling him.

We cannot have funding for an elevator in our home even though my son is house bound for most of the year due to his frail health and susceptibility to the weather. We moved from a brand new tri level home on a terraced block at great financial loss to ourselves into a two-storey home on a relatively flat block. We were told by Home Modification Representatives that we are essentially entitled to nothing and should take what they offer, which was completely ludicrous and offered us no acceptable solution and therefore we haven't pursued this option. We believe that our son needs to be able to access all parts of his home and has the right to go wherever his family members go and we are putting in an elevator at our own expense.

Early Intervention providers such as DADHC and Northcott Society have a complete lack of equipment for loan. The therapies offered are very general and the regular changes of staff mean that there is no consistency or follow-through with the same advice being given over and over again as staff come and go. I felt much of it wasted our time. There are certainly no major centres available to us as there are in the US whereby all of the therapies come together and treat the shole child with loads of innovative equipment on an ongoing basis. It is very isolated, disjointed and behind the times here.

In trying to provide stimulating environment for our son to develop and grow we have spent tens of thousands on equipment, toys and learning materials; these include standing frames, toy and communication switches, communication devices, a touch screen computer, numerous software applications, a switch-adapted mouse, a walker, arm orthotics, leg and arm wraps, adjustable tables, seating systems, etc. I have had to import equipment from the US as the equipments is either unavailable here or far more expensive than getting it directly. We have done most things on our own without therapists helping as they generally do not advise you on what's available. We have had to become therapists to help our son properly and we have paid for almost all of his equipment ourselves, bar a wheelchair and a commode. We even found the doctors where behind other countries in diagnosing CP and refused to give him a proper diagnosis. Once we made the case, again researching ourselves, we finally got the proper diagnosis and are now on the waiting list for the Spastic Centre. It has been a year and could be another year, yet.

We were encouraged by the physio at our local hospital to apply for funding for AFOs. We had his legs plastered in anticipation but he has had to wear the plaster daily for 6 months as the funding is not yet available. His strength has dwindled and his hips will soon require an operation due to the lack of weight bearing.

We feel that the system wastes thousands of dollars on bureaucracy and there is consequently no funding for even the most basic of equipment. The families end up paying for what they need.

**What We See As A Solution:**

- We would be far better off if we could access funds ourselves and pay for the therapists and the equipment that we needed when we needed it, instead of having to wait.
- Proper Early Intervention is necessary so that kids are given the best start that they can have and more serious and costly problems are thwarted.
- I believe the National Disability Insurance Scheme is a great prospect as it gives parents, carers and the disabled the opportunity to spend money on things that they KNOW they need and can access the funds and equipment in a timely manner.
- Stop the wasted money on bureaucracy and allow the commercial nature of "parents buying what they need" to drive the sector. There are too many ill-equipped therapists who are wasting people's time. People will pay for good services and the lesser services will be weeded out.
- A timely purchase of equipment and services is very important to stop the degradation of skills and quality of life for the disabled and also for their carers who can suffer major injuries while waiting for funding for hoists, etc.
- The system is unfair in the parents like us are having to pay for things with our hard-earned POST-TAX DOLLARS. I have begun resenting paying tax since my son's birth as I always assumed it was going to those in our community who needed help but now I know it is not.
- If parents had funds they could purchase things such as respite when they needed it.
- We feel that a system that assesses a person as to their lifelong requirements and reassesses every few years and then allocates funds to use for their care, with a tax-free status, much the same as a compensation payout, would be much farer to people like us who are paying for everything ourselves on post-tax dollars.
- Taking away the necessity to have therapists assess what a person needs is important as it promotes a reliance on therapists that you maybe don't even need to see or whose opinion you don't agree with. There are plenty of therapists that have got my son's requirements totally wrong.
- If I had the funds directly my son would have had AFOs years ago as I was constantly being told he didn't need them. I knew he did. The Spastic Centre finally said he did and I had to go to a rehabilitationist to get a prescription which cost $380 for the first visit. My son's leg then had to be plastered three times to get it back into shape. He hasn't been standing so the rehabilitationist says he needs a hip operation now. All of this could have been avoided if we had the AFOs that I knew he needed. The red tape which surrounds getting even the basics is ridiculous and costly for the government as well as ourselves as our son shows, having to have plastering done and an operation to correct his hips in the future. All to save on $1300 worth of AFOs.
- Institutions do not necessarily spend their dollars in the best way they can. We have taken our own modified chair to playgroup at Northcott as there wasn't a supportive chair for my son to sit in. I could have taken him to the local playgroup and got the same service. Equipment is vital for my son to be able to access any type of play. This is ridiculous as all of the therapists will tell you that trunk support is vital for kids to be able to use their hands properly.
- In education, funding should follow the child so that either they can be homeschooled or attend the school of their choice, whether public or private. We provided the local school with a computer and various communication devices and it was still inadequate. The only other options were the local SSP or the local public school, which were both out of the question for him. There needs to be more choice.

Thank you

Regards,
Amanda Hanna