Something to think about...

In 2010 what kind of future can a seven year old boy expect as he grows up in Australia?

You would think he would be given every opportunity to learn, to thrive, to be a valued and included member of his family and community, to have friends, an education and eventually a career. He may also plan on having a family of his own, be a home owner, have a car, travel...

But what if that seven year old had a disability.

Sadly it is a very different story.

The system meant to support those with disabilities in Australia is broken.

The 'default setting' for a child with a disability doesn't include any of the above assumptions – the promise of an 'ordinary life' is not guaranteed unless they have a family prepared to fight for it, at every turn, on their behalf.

The government bodies, service providers and Not-for-Profit organisations meant to help are, in fact, the blockages in the system. Too many bureaucrats and workers in the disability field actively deny an 'ordinary life' to a person with a disability.

Power and control must be given to the person with the disability – for too long we have kept people with disabilities vulnerable, devalued and marginalised.

Many organisations will argue that the power should be in the hands of the Government, Service Providers or Not-for-Profits. Other organisations will plead the case of the "carers" (the reality is if the person with the disability is being supported then, by default, so too will the carers). **The only way a NDIS can actually change the life of a person with a disability is for the person with the disability to be in control. Any funds must be self managed by them or their chosen representative/family members.**

Currently government money is poured into the system but unfortunately it isn't making it to the 'coal face'. The people with disabilities are NOT being supported effectively by the current multi-layered, fragmented and broken system.

The myriad of programs, schemes and welfare payments need to be consolidated and then supplemented via a Medicare style scheme to help provide for a NDIS.

Currently, we have a system where workers in the disability field are assured of their wages first, and then services are provided from the left over funds – this needs to change. The OH&S of a worker trumps the HUMAN RIGHTS of the person with the disability - vulnerable people are kept vulnerable and marginalised under the current system.

If the person with the disability has the power to choose where they get services, where they buy their equipment, what therapies or medical treatments they wish to pursue then all of a sudden we have a viable system – a normal, consumer driven system – not a system created by the providers to support the providers and the crumbs used for those it was originally intended.

So what's our experience...

Our son (Mac) is that seven year old boy who deserves a brighter future. Mac has multiple severe disabilities as a result of an acquired brain injury at six months of age. Mac's brain injury is so severe the medical profession claimed they had "no options in their armoury for a kid as 'bad' as him". Mac has Cerebral Palsy (severe spastic quadriplegia and significant cortical vision impairment).

This left us to look outside the mainstream options at great financial cost – there is no funding available for non-mainstream therapies.

Initially we took Mac to overseas three times per year for a physical therapy program which proved to essentially safe his life. Despite being at the severest end of the physical disability spectrum Mac is now a very well, healthy little boy albeit still very physically disabled. The cost to us as a family was $25K per annum and approximately three hours per day to dedicate to physical therapy just for his physical therapy program. We have self funded almost every other aspect of Mac's needs with the exception of one seating system provided by the NSW PADP scheme.

Mac's whole life has been one fight after another. The difficulty is not his disability but the red tape and bureaucratic blocking we face every week of his life.

Mac is a child who, despite his significant physical disability and vision impairment, haws NO cognitive impairment. Mac attends his mainstream local public school. He is supported quite well at school – but still retains very little control over his environment and the supports provided.

He would like to be a Maths Teacher at University when he grows up. I often wonder how I should tell him, as the system currently stands, that...

> ***"his country does not believe he is worth 'investing in' so he can become a tax payer and that, in Australia, we would rather waste money on 'warehousing him' in day programs for 65 years once he leaves school".***

We are limited in options for appropriate service providers because the skill set, vision and expectations in Australia is not as good as it could be. There are organisations such as the Spastic Centre of NSW who even have a system of "red flagging" therapies or communications options they don't believe in and deny a family the right to choose those therapies or communications options by refusing to support them in their choices.

We took Mac to our choice of communication expert in Victoria, outside our home state of NSW. In of our first appointment she was able to provide Mac concrete yes/no options using foot switches and voice output technology. In less than two hours she achieved more than we have managed in six years of Early Intervention and specialised Speech Therapy in NSW. Mac has since gone on to learning how to type in Morse Code with his foot switches in just a matter of weeks. This is why Mac can envisage a future, with a career. It won't be easy, he will need significant supports, but if "a kid as bad as him" can have goals, dreams and options they why can't everyone. We just need to remove the 'blockers' from his life.

The person with the disability needs to drive the process, to be in control of their life. Families won't waste money on useless, irrelevant services, they will do the best they can because, at the end of the day, their lives or the lives of their child depend on it. This can't be said for the current service providers.

We need to start now, regardless of whether an NDIS is established. All individuals should be able to negotiate individualised funding, if they don't need respite they should be able to "trade it in" and access more flexible funding to help them get what they do need. The Carer Payments scheme should continue until an NDIS is established but needs to have any means testing/income testing removed as a top priority. The threshold for cut-off is too low – there is only a small percentage of children eligible for this funding and they should all be supported regardless of income of their parents.

The power and control must be given to the person with the disability – they may choose to hand over this control to a service provider, that is their choice, the default must NOT be with service providers.

Mac's future depends on this country getting things right – fixing the broken system.

I don't want to have to tell my child that despite him fighting to stay alive, defying the odds and being as determined as he is at school that his country doesn't think he is worth investing in – do you?

Regards

Gina Wilson-Burns