Here we are again. Last year I made a submission to the Inquiry into Better Support for carers. In that time nothing has improved for carers or the people they care for. The little people are offered are crumbs given in the hope you will give up, or to keep you quiet for a while and maybe think something might improve. We don't want $600 a year, we want systemic change.

I have a ten year old son (Nicholas) with multiple disabilities. He has intellectual disability, severe autism, is profoundly deaf, has cerebral palsy, hydrocephalus and myriad medical issues that have required medical intervention or surgery. If you think the above sounds bad, try living with it!

You might think with all the above disabilities/needs Nicholas might have priority access to as much assistance as possible. If you think that, you would be grossly naive and have no knowledge of the third world disability system that exists in this country.

Basically disability funding as it stands currently is a privilege, not a right. That is the inherent problem. My understanding is that in some countries such as the U.K and the Netherlands, disability funding is automatic.

In Australia you have to fight for the few crumbs handed out by governments and administered by supposedly well meaning organisations who then treat you with contempt.

I will give you some examples. In Victoria most funding comes from DHS (Department of Human Services) but it is not as simple as that and never transparent. Various monies goes to UCCO (Uniting Care Community Options) and to Yooralla and to other disability organisations.

Many times our family has been in crisis because of Nicholas' high care needs and frequent surgery. In 2007 Nicholas had two brain shunt surgeries within a month (July 2007). I was really depressed and feeling our life was without hope. I needed respite from my caring role and case management for Nicholas' many issues. I contacted DHS pleading for any help they could give me. They told me their waiting list for assistance was very long and I would be better off applying to UCCO for long term assistance. I believed them and duly applied to UCCO for long term case management. Guess what? I'm still waiting!

In September 2008 Nicholas had very difficult and complex hip surgery in which his hip was cut and rotated. It was a nightmare. He was in plaster from his belly to his feet and totally incapacitated for many weeks. For over a year I had fought UCCO for any information on our application. Always the answer was: there's a long waiting list, sorry.

When Nicholas was at the RCH (Royal Children's Hospital) in Melbourne, the Social Worker in the Orthopeadic Ward was aghast that Nicholas had no case management and promptly made it her business to champion him. She went ballistic at some senior people at UCCO and asked that he be given priority. Even with her efforts all she could obtain for us was short term management for six months.

The disability system is broken beyond repair and must change. The change cannot be cosmetic, it must be systemic such as the NDIS being proposed.

To give you an update we are still waiting for the services that Nicholas desperately needs and that we cannot and should not have to afford. We have applied for an ISP (Individualised Support

Package) with DHS. We have been sent a letter saying his funding has been approved, but have received no funding. We have been told Nicholas is on a DSR (Disability Services Register). What does that mean? Your guess is as good as mine! We're told it's a register of "need" not a waiting list, so if someone's need is greater, they'll get bumped up. I suspect someone has to die or move to another state/country for there to be any movement to the Register!

Despite letters, phone calls, referrals from health professionals declaring Nicholas' high needs and referrals from my psychiatrist stating our family to be in crisis, it makes no difference. We are still waiting for the basic services Nicholas requires.

To add insult to injury, at every step you have to justify your requests. Nicholas is totally non-verbal and incontinent. One of the things we requested in our ISP was specialised toilet training for children with autism. This was around $5,000. You would think we were asking for the earth, the hoops we were put through! Why was the school not providing this? They weren't and haven't. The handballing is beyond belief, you wouldn't believe it until you're one of the many unfortunates that's going nowhere in the system.

To end this, I've run out of energy. I and thousands of parents like me have to fight "the system" everyday. It shouldn't be this way. The change needed is systemic. Organisations like DHS can't have a monopoly and dictatorship by bureaucrats, deciding who is worthy to get what, must end.

It must be a basic right that if you have a disability, then depending on your level of disability you get a sum of money guaranteed for life. That money must be enough for therapies, respite for your family that cares for you, opportunities for recreation where you are adequately cared for and last but most critical suitable accommodation if and when your family can't care for you.

The above must be a right, enshrined in legislation and guaranteed according to need, not left up to bureaucrats to decide.

I can be contacted on any of my comments and most definitely wish to be kept informed of the result of this Commission. Parents like me are not going away, nor are our children. Unlike parents of former generations, we won't be quiet. The time to change the disability system is now.

Cynthia Pereira