

My four year old son was referred to CDS following a diagnosis of paediatric Graves' disease. This is an extraordinarily rare disease on children so young, and he is only the 5th known case in the history of medical literature in his age group. As a consequence of his disease, he has suffered a thyrotoxicosis, required an emergency thyroidectomy, and will live on thyroid replacement for the rest of his life. His disease has caused osteoporosis, and he has suffered dozens of fractures to his legs, which has led to significant pain and debility. Graves' disease itself causes significant proximal muscle weakness (hands, arms, legs) which impacts his strength, balance, gait, coordination, gross and fine motor skills. This means that essentially all elements of being a little boy is harder for my son than it is for most other kids. He also suffers significantly disordered eating and speech difficulty secondary to the large goitre he experienced prior to his thyroidectomy. This goitre led to dysphagia and choking, causing him to fear eating, as well as changes to the soft tissue structures in his throat and palette- affecting his capacity to swallow and articulate speech.

He spent months of his life in and out of PCH for treatment and surgery before completing a 12 week bout of intensive rehabilitation, and was then referred to CDS by the intensive rehab team at PCH for desperately needed ongoing rehabilitation. His rehabilitation needs relate to ongoing weekly physiotherapy, occupational therapy and speech therapy, as well as the need to see a paediatrician to monitor his developmental delays.

We were relieved to have his referral to CDS picked up and actioned for an initial appointment quickly, however our relief quickly turned to despondency when at the initial consultation we were informed that despite our son's overwhelming and desperate need for services and rehabilitation through CDS, he would experience massive delays and limitations in accessing these services.

For a child who cannot walk without a limp, has poor balance, gait abnormality, chronic pain, a bone disorder that requires physical therapy to treat, and a significant risk of serious injury (more fractures, extensive fractures, debility etc), he faces a wait of over 9 months for physiotherapy. Should he finally be seen, he is only entitled to 6 sessions with a physiotherapist via CDS.

For a child who has receptive and expressive language delays and significantly disordered eating, he faces a 12 month wait to see a speech pathologist and again, is only entitled to 6 sessions with a speech pathologist through CDS.

For a child who has significant gross and fine motor deficits and difficulty with balance and coordination, which impacts on his safety as well as daily activities of living, he faces at least 12 months wait to see an Occupational Therapist via CDS. And again, he is only entitled to 6 sessions.

We have also been advised that the wait time to see a paediatrician through CDS is over 2 years.

These significant wait lists mean massive delays in access to care for kids like mine, who continue to struggle and fall further behind in that time. The number of sessions offered to children like my son are woefully inadequate and go nowhere towards providing him with the therapy that he requires to live a safe, active and fulfilling life like other kids. His illness and needs are no fault of his own and yet he will suffer further than he already has because of the barbaric inadequacies of this system. The added insult is that he will ultimately require more therapy for longer because of these delays. Offering us parenting classes (which is what has occurred as if to make up for the massive delays in access to care) will not assist my son to recover from my physical illness and extensive physical needs.

As a family, we are facing the reality that we are going to have to choose which therapies he needs the most (meaning that he misses out on therapies that he needs), and find a way to self fund hundreds of dollars worth of therapy and therapy tools ourselves each week. To say that this is frustrating is an understatement.

The current system is desperately inadequate, offensive, and failing vulnerable children in Western Australia. Our kids deserve better, and it's embarrassing that we live in the richest state in the country but see no value in providing an extensive, safe and accessible service for our kids and families.