Submission:

I am a mum of a young child with Angelman Syndrome. As such my daughter has multiple impairments - physical, sensory, intellectual - she is expected to be non-verbal for life. This syndrome affects every part of my daughter's development. The long term prognosis for her is constant care for the rest of her life.

So what happens after your child is diagnosed with a syndrome? Is there a case worker to help you through the maze of agencies, funding, therapies, respite? The answer is no - you leave your paediatrician's office and go home to deal with it. If you are lucky there will be a parent group that you can go to for advice. But if you are part of the many rare diseases and disorders then you are pretty much on your own.

For all parents this is heartbreaking news, and you would imagine that our government agencies would make your future easier as they would understand the magnitude of this news, and the affect it will have on your life. Sadly, again, the answer is no. There is a myriad of paperwork to be completedly, you must reprove your child's disability to every agency that you encounter, deal with centrelink officers for your measley $100.00 a fortnight carers allowance. There are wait lists for services, lack of physiotherapists, and lack of funding. Due to the way that the Queensland Disability sector is set up, if you try to access disability services whilst going to an early intervention program through Education Qld, you are told that you are "double dipping". You tend to hear that term a lot whilst just trying to access basic services.

You rely on other parents to get information on how to access services, which services to access, where the wait lists are, and who are the best to approach. The disability sector in Queensland is supported by parents helping other parents. Without this the system would be completely paralysed. But to be honest parents are the ones with the least amount of time and resources to be able to provide this.

Suggestions:

* It is suggested by our family, and those around us, that the sector is centralised with case managers. Upon diagnosis (or upon a general diagnosis of global development delays), you are referred to a central agency and provided with a case worker. This is the person who makes sure that your family is cared for - speech therapy, physiotherapy, occupational therapy, respite and funding.

* Families should only have to prove their child's disability once through a central database. Agencies are then referred to the database to check on the child's disability. As a general rule kids with disabilities don't get better - a child with

Angelman Syndrome will always have Angelman Syndrome and will always require assistance. There are no magic cures. The system needs to trust in parents that they won't try to access services that aren't needed - nobody wants to put their child through speech therapy unless it is needed - it is exhausting beyond measure.

* The majority of families with a disabled child are on one income. There is little funding for one-on-one aides to put children into childcare. For example, my daughter has funding for 5 hours a week one-on-one care through her child care centre. That doesn't even equate to a full days work. We are lucky that our child care centre hire our aide for the whole day to enable me to work one day a week. And I'm lucky that I have an employer who is willing to hire me one day a week. But this could all end at any time as I am relying on the kindness of strangers and companies to see me through this. There needs to be increased resources so that our families can return to the workforce. The families that need the most amount of extra funds, are the ones who have the least amount of opportunity to work. I also have respite lined up through family managed funding - but this is only for four hours a week.

* Reduction of the Medicare threshold for families with disabilities that include health concerns. My daughter also has to see a neurologist, opthamologist, paediatrician, dietician. These all add up for a family on one income.

I hope this submission is useful. The sector is in desperate need of overhaul, not just a reshuffle which is occurring in Queensland at the moment. Most parents view this latest reshuffle as just another waste of time and funds, with no real benefit to the parents.