Suggestions for National Disability Support Scheme

Background - I am the mother of a five year old little girl, India, who was born prematurely at 28 weeks. India spent three months in the neonatal intensive care unit and eventually came home on oxygen. For the first three years of her life India was often sick requiring frequent hospitalisations. India has also required several operations, many general anaesthetics, a lot of tests and frequent visits to specialists. India has severe quadriplegia cerebral palsy, epilepsy, is deaf and is unable to eat food orally so is solely tube fed. India requires full assistance with mobility and personal care and always will.

1 When first diagnosing a child there should be a central bank the child's name is placed on with the states relevant disability department. A case worker should be then allocated to make sure relevant services are organised, the parents are made aware of government allowances/pensions and most of all support and counselling offered. Having your child diagnosed with a disability is a traumatic event and a life changing one.

2 A central bank of disability service providers should be put together. As it stands now services are fragmented and it is by trial and error you discover them.

3 Connect families to other families in the same situation. This has been the most important thing for me in being able to cope. Feeling like you have your own community you belong to. Whether it be a yahoo internet group, meeting face to face with other parents or a phone group. I think it's important to include fathers too.

4. Make things easy for families requesting disability equipment. It wears you down having to write out applications and waiting for months for funding to come through. Why is it acceptable to wait for a year to get a wheelchair for your child? It's not like that in other countries.

5. Provide respite care for families so they can catch their breath and go on being the best parent for their child. This should include in-house and out-house options and also registered nurses if needed for medically fragile children. This is most important when parents are sleep deprived attending to a child around the clock.

When India is sick even with a virus she often has difficulty sleeping with fever and spasms.

Now India is more robust I so appreciate this as there is nothing more stressful and tiring as looking after a sick child with multiple medical conditions.

6. Due to the brain damage causing the disability many children also have problems with their sleep. Without medication India used to be up half the night. I can only imagine what that would be like if your child was able-bodied and able to get out of bed and walk around the house. For those parents there would be no break. Once again respite is a necessity.

7. Why isn't there rehabilitation hospitals for young children? Early intervention programmes usually only provide a face to face service 1-3 hours a week. Why aren't there rehabilitation hospitals where children go for intensive therapy in the formative years. This could also double as a place to provide respite for parents while they live in.

Bear Cottage in Manly, Sydney is a wonderful example of a respite centre where the parents stay too but care of their child is handed over to nurses.

8. Keep in mind that families with a disabled child are often disadvantaged financially. It is impossible for me to work any more than one shift a week as I spend my time attending to India and driving her to her school which is an hour away. There should be tax rebates on therapies or disability equipment such as hoists, modified vehicles, etc.

9. By law there should be equal opportunity for children to attend child care centres and pre-schools. Government subsidies do not cover the full amount it costs to support a child with high needs so centres quite often do not accept children with disabilities. India was not accepted at our local childcare centre so once again another barrier for a parent to get even part-time work. Currently she has been accepted at a kindergarten but as her carers salary

is not fully covered by the government subsidy there is pressure on me to fund raise for the kindy.

10. Some service providers provide a fantastic service. Some examples of this are the Royal Institute for Blind and Deaf Children, Sydney Cochlear Implant Centre, Australian Hearing and the Matilda Rose Early Intervention Centre in Sydney. Professional, conscientious and caring. Deaf services in Australia are excellent. However, services for the physically impaired are seriously lacking. I have accessed services in NSW and QLD and both not for profit organisations and government departments are inadequate and underfunded.

Dealing with service providers is the bane of my life. Most the time there is not much service at all, you have to call often to get follow up on anything you have requested, you are not provided with enough emotional support, education or information on other services you might be eligible for. Examples of this are DADHC, Spastic Centre, CP League and DSQ.

11. Most important! Allocate funding directly to the disabled person or their parents. At the moment I see service providers spending money on staff salaries and maintaining buildings and whatever is left over is spent on the actual clients. As a parent I could spend the money on what I thought my daughter specifically needed. Physio of my choice, a carer of my choice to provide respite locally, buy needed equipment quickly. It would also make these service providers accountable. If the service was inadequate then parents would go elsewhere to pay for service.

12. Support a national disability insurance scheme.

13. Change the mentality. If you are sick you expect a hospital to be there if needed. If you have a young child you naturally expect they will go to a local school. Why if you have a disability do you have to beg, mooch around and justify to various service providers what you vitally need for your child. Often you are fobbed off to approach charities. And we live in a first world country!?

It is difficult enough for some parents to cope with having able-bodied children let alone a child with special needs. I hope I have given some insight into what it is like to be in this situation. I believe the government should do all it can do in its power to protect our children by providing adequate therapy and services for them and to nurture the parents who care for them.

Kind regards,

Nicole Thompson

I am happy to be contacted or assist in anyway I can.