

SUBMISSION FOR INQUIRY INTO DISABILITY CARE AND SUPPORT

My name is Yvette Mavrothalassitis and I am a mother of two sons, a 6 year old and a 4 year old. My 6 year son has Autism. I am extremely concerned for his future and the future of other children with this disability. The level of support that is available is not sufficient. I have petitioned to the government and the reply back was appalling. Various areas needed to be addressed and altered are:

- * Diagnosis
- * Early Intervention
- * Financial
- * Support
- * Education
- * Long Term Support

DIAGNOSIS

GP's should have a better understanding of Autism, PDD-NOS, ADD, ADHD and other related developmental delays. They all should follow a strict criteria/process that doesn't leave parents with false hope. Eg: a GP told me my child may have very mild Autism, but that it's ok because he can be cured. Then when referred to a Paediatrician, the waiting lists parents have to face is a joke (considering how critical early intervention is) and too costly. Once diagnosed parents are sent on their way without knowing where to turn to next. The whole process is 'cold' and 'detached' and it's not what parents need when told their child has a lifelong disability.

EARLY INTERVENTION

Early intervention has proven vital in improving children with a disability, but there is not enough available and we are faced with limited places and long waiting lists again! Government funding is poor for early intervention providers which then means there are not enough places for all of the children in need. Then fees rise because providers have no funding and families are shut out because they just can't afford the costs and the children then go without.

FINANCIAL

* Carers Allowance is not enough! \$100 a fortnight covers nothing!! Eg: a half hour of speech therapy starts at \$90-\$100 and needs to be done weekly. This allowance needs to be increased.

*Carer Payment needs to be available to more people. Criteria needs to be re-evaluated and not as strict. Disabilities are more than just physical!!

*Bulk Billing needs to be available across the board as soon as a disability is diagnosed. The amount we pay for a child with a disability is way too much.

Eg: - paediatrician fees	- blood tests
- speech therapy	- occupational therapist
- physio	- specialists
- preschool	- prep class
- early intervention school	- cranial therapy
- computer/printer/laminator supplies	- dietary needs
- safety features put in the home	- dietician/nutritionist
- parent training	- psychologist / psychiatrist
- counsellor's	

Please look for reference into: 'Economic Costs Of Autism Spectrum Disorders' from aeiou - April 2007 and also Research Report No 16 - 'The Nature and Impact Of Caring For Family Members With A Disability In Australia' by Ben Edwards, Daryl J Higgins, Matthew Gray, Norbet Zmijewski and Marcia Kingston.

Too many families are being taken for granted!! Business's are asking for exorbitant amounts for services that they now families need. Eg: I was charged \$270 to talk to a certain service provider face to face on what was available for my son. Then to be told that to give him an assessment on school readiness would cost us \$6,000. This is unacceptable!!!!!!

* Extra income support for low income families.

* FACHSIA funding is not lenient enough. Government supplies families with Autism funding of \$12,000 until the age of 7, but I can't pay for preschool fees that are for a supported placement. I also can't pay for school fees at ASPECT. The funding is for Autism specific support but my child is attending ASPECT School for Autism and we can't use it for that. If

he didn't have Autism he wouldn't be attending such a school. A provider has to be 'registered' for money to be used, but not enough different services are registered. They haven't made it that easy for services to be registered.

SUPPORT

- * Families need a lot of information as soon as a child is diagnosed - this is not happening now. Instead we're being pushed on our way.
- * Respite needs to be available to all families and not to be like a 'lottery' or like an animal auction.
- * All families need to be linked to a case worker to help and guide them through this process.
- * More support groups need to be available for mothers, fathers, siblings and other family members. Everyone in your circle suffers when Autism is present.
- * More training for parents on all aspects of concern.
- * The Enhanced Primary Care Plan and the Mental Health Care Plan is not enough.
- * The new Medicare items are not enough.

EDUCATION

- * There is not enough Autism Schools, Special Schools and IO classes in mainstream schools
- * Schools are not catered for children with a disability.
- * Fences and childproof gates are needed in all schools and they must be locked during school hours.

When I asked principals on why there isn't more IO classes or Autism specific classes in mainstream schools I was informed (by more than one) that the government doesn't believe there is a need for them. Have no doubt, every school needs classes for disabled/autistic/delayed children. Every one!!

- * School fees for our kids need to be funded.
- * Schools need to run programs to raise awareness of disabilities such as Autism and set up buddy systems for children so they are accepted.

LONG TERM SUPPORT

* Without implementing early intervention and educational needs, the long term future for our children looks bleak. The government needs to spend money fixing this problem and supporting our children now or they'll pay more in the future when they are not able to support themselves.

* For younger/older adults they need training programs, job support placements and financial support - not just a measly \$200 a week on disability pension. How can they create a life for themselves and live independently on that???

* More support housing that enables its occupants to relate and be a part of society.

I do hope the future of disabled people in Australia is going to be a lot better than it currently is because at the moment it is shameful!!

Regards

Yvette Mavrothalassitis