Submission to Productivity Commission
By Queensland Angelman Association

Queensland Angelman Association is an unincorporated group of parents and carers focused on providing support and information to Queensland families who have been touched by Angelman Syndrome_(AS). It is our goal to open a channel of communication and support between Queensland families.

As a result of our contact with Angelman Syndrome families we have become aware of the service gaps and inequality within our current disability sector. Some of the areas which have been brought to our attention are as follows:

- **Funding by Diagnosis**
  We are seeing current government policy for early intervention funding based on diagnosis, rather than need e.g. current funding available for kids with autism; and recent Labor Party policy providing early intervention for a "list" of particular disabilities/diagnosis. Whilst this provides the benefits of early intervention to a particular group of children, it sees a great number of children whose diagnosis is not "listed" falling through the cracks of the system. If you have the wrong diagnosis, no early intervention funding for your child. This is particularly detrimental for those disorders which are classed as rare as they lack the numbers to lobby for change. For example, Angelman Syndrome requires intensive early intervention on all levels, physiotherapy, occupational therapy and speech therapy, however under current government policy our children are not eligible for these funding packages.
  Solution: Funding for early intervention should be provided on the basis of need, rather than diagnosis. All children with a disability should be provided with the same benefits.

- **Lack of a centralised system.** We are discovering that parents are quite often wasting time chasing services between different governmental funded organisations due to the lack of central information available. Unfortunately information is more readily found through other time deficient parents, than it is from the current network in Queensland. The simple act of finding basic respite for our families can entail days of telephoning the numerous agencies. Individual agencies have differing geographical and service boundaries, levels/types of disability or ages that they support. Once you find a service that can assist there is a vast amount of paperwork to be provided, again, by parents with an already demanding schedule. The current lack of centralisation and assistance is particularly difficult for families who have just received a diagnosis and are learning to navigate this most complicated area. There is clearly no support or advice provided.

Solution: A centralised system whereby your are designated a case worker who can provide advice and apply on your behalf of your child's needs. Alternatively for those families with some experience in the sector, funding allocated to families, allowing them the flexibility to find an appropriate service provider.

- **Lack of therapies available in regional areas.**

The level of therapies available for your child can be dependent upon where you live. There is little equality in service provision throughout the State. By way of example, one of our Queensland families have been without a speech therapist and physiotherapist for over six months. Angelman Syndrome children require intensive physiotherapy to enable them to master their gross motor skills and intensive speech therapy to enable them to communicate their needs and wants. It is not a luxury for our children to be provided these services, but an absolute necessity and as such should be treated the same. **Solution: If therapists are not available within regional areas, parents are provided with individual funding to access the private therapies that are required.**

- **Lack of childcare and before/after school care.**

This is a very important point for our families, and one which is fraught with difficulties. Despite the age of our AS children, most families require some form of childcare or before/after school care to assist working parents. Whilst these facilities are easily accessible by able-bodied children, they are hard to find for children with a disability. Funding for childcare aides is scarce, and in most cases the mere 5 hours a week provided does not even cover one full working day. For our older school aged children, there is also a lag in services. They are too old for the conventional childcare system, but many of our schools do not provide after school care services for children with extra support needs. There is endless rhetoric in government glossy leaflets outlining plans for inclusion, but in reality there is very little practical support or funding provided. Families feel this is simply lip service.

This inadequacy is best relayed by a family who are struggling with the current system:

> *As the parent of a disabled child we qualify for in home care. That means that if we have an approved carer work in our home we can claim the childcare rebate (50% of out of pocket expenses) and the childcare benefit if where eligible (a reduction off the hourly rate). At the moment, approved carers are primarily the family day care scheme and wait lists are years long to find someone (if at all) or if we can find our own carer they must register with the agency and pay their own costs to register often around $400 (insurance costs). If you are only looking for a low number of hours there is little incentive for someone to*

register and the family start from scratch if that carer moves on. Make it possible for families to broker hours off existing service providers (who already have the insurance programs). The service providers are reimbursed by the family, the carer is covered by the service provider and is paid through their system (reducing likelihood of cash in hand, under the table schemes) and the family can claim half the expenses back through the child care rebate. These service providers are already monitored for service standards through HACC schemes and audits. Families can keep working to pay for the costs of their child and contribute to the economy therefore reducing the likelihood of them dropping out of the workforce and onto welfare programs.

Solution: Supports and aides for inclusive childcare for all ages should be made a priority to assist those working parents. Government supported before and after school care provided within our special schools to enable working families to continue.

- **Reproving your child's disability**

Due to the lack of a central service/advice base, there is very often the need to reprove your child's disability when applying for services, respite, therapies etc. For most parents this is emotionally and physically draining, and very unnecessary. This additional paperwork also creates a burden for doctors and therapists.

Solution: A secure database that can be accessed by service providers confirming our child's impairments (i.e. global development delay) or details of diagnosis. We would suggest this could be linked with the current Carers Allowance through Centrelink.