PRODUCTIVITY COMMISSION's – DISABILITY CARE AND SUPPORT

BACKGROUND

I live in Sydney and base my concerns around NSW disability services, ADHC and the service providers they fund. My issues will mainly concentrate around children with complex behaviours.

I am a 48 year old mother caring for a daughter, age 14, with autism and severe/profound intellectual delay. I have 2 other children, another daughter, age 16, and a son, age 10. I work 2 days per week. I have a husband whom is self employed and is away from home for approximately 70 hours per week.

My daughter with autism has challenging/complex, aggressive, self injurious, anti social and inappropriate touching behaviours like sticking her finger up her nose, masturbating and spitting. She has none to limited self interests, no obsessions apart from water and motion activities like driving, ferries, trains etc, lots of dysfunctional behaviours and an array of sensory issues, most particularly hearing sensitivies, especially crying and noises of small children. She is also totally non verbal with limited augmentative communication.

She has disruptive sleep patterns and may be awake for up to 3-4 hours at night with behaviours and disturbing the whole household. MY children routinely sleep out of home, at their cousins, so they can get a good night sleep and some quiet time with a "normal" family.

Because of these behaviours my family is limited in our social interaction and activities we can participate in. As a family we have not had a vacation in excess of 4 nights for the past 16 years. My kids have never been on a holiday for any extended duration.

Because of my daughter's inability to entertain herself she will continuously require your attention for her own needs leaving little time for the rest of the family.

We cannot speak/communicate as a family because when my daughtetr hears voices she will come and pull you away. We need to lock ourselves in a room to discuss issues – until my daughter finds us.

As a result we cannot do things most families take for granted, eg: We cannot:

Have friends/family over for extended periods of time
Speak in a motor vehicle with my daughter present
Attend church
Go for walks, picnics, camps
Visit family and friends
Shopping
Movies
Appointments
Attending to my elderly mother, age 84 with severe dementia
Socialising with my other children
Sit at a dinner table for the duration of a meal without a temper tantrum or other interruptions

I have so much to say so I will just list in point form – a bit of "brain storming"

THE PROBLEMS WITH THE CURRENT SYSTEM (apart from shortage of services)

POLITICAL ENVIRONMENT

- You stated 600 submissions were received to Feb 2011. That is **less than 1%** of 360,000 people with a disability (your target group). That is pathetic. In Australia there is no voice for disability. We need more noise before the government will ever take notice. We need more carers to complain.

If only 300 families caring for children with the severest disabilities left their children at Parliament House on one given day can you imagine the situation the government would be in – where would these children be cared for? Perhaps then we would get government attention.

We need one courageous, brave and smart parent to successfully sue the government for lack or insufficient help in caring for their child with a severe disability. As a result they would be seeking damages for emotional and psychological stress, financial loss and relationship breakup. WOW would that open up the flood gates.

Only a month ago a Sydney girls catholic school was successfully sued for damages following insufficient school intervention following a girl being bullied at the school for some years.

Sadly, we require an inquiry into disabilities, costing the government more millions of dollars before disability funding is seriously looked at. The government has known for years the predicament families are in but because carers accept their role out of love and dedication the inequities and lack of services continue. What are the alternatives.!!

- As for federal funding – Australia has all the funding for “ an education revolution” – a project that saw a massive over spending of billions of dollars because of the contracting out of labour and minimal supervision on costings and what the school actually required. We have $500 million pledged to Indonesia for building of schools over the next 5 years, the home insulation debacle costing again billion of dollars and the list goes on.

The government could think up a super mining tax at the click of their fingers to fund superannuation. Superannuation is of little benefit for families caring for children with severe disabilities because the opportunity for both parents to work fulltime or hold down a career of substantial nature is dismal. The government could not consider for a moment perhaps a couple of billion could be used for disability services**. Our group is not important enough – it won’t gain votes at the next election!!!**

Additional several billion could easily be injected into disability services if the government wanted to. A lack of management of funding is hugely the problem in addition to the lack of funding.

OTHER ISSUES

- **Is the hierarchy in ADHC required?** All the senior project officers, project officer, senior managers etc. How many project officers’ do you need?

Services are already stifled with policies and procedures. This is so little flexibility and everything is an OH & S issue.

Public companies answering to shareholders undertake an investigation of operation efficiency when their profits dip. Why should this not apply to government organisations, or are we waiting for another public enquiry. A massive investigation regarding the operational efficiency of ADHC, service providers and the costing of services could prove useful. From this alone millions could be saved!!!!!

- **Do we require all the service providers.** With each service provider there is a hierarchy of management and that means **cost in salaries.** Each service provider provides similar services but all with their own ceo, directors, management team.

I personally think the disability services are “over managed” and we can do with fewer providers but more services for the providers that remain. ADHC can provide and increase their role in providing of services.

- **Case management, advocacy, appeals and complaints should be funded and operated by external organisations with no government ties.** It would be great if our banks, mining coy’s and large retailers could fund this. There is a mutual respect between the government and these organisations. There would be independence, autonomy and non bias approach which is flawed in the current system. ADHC case management – is doubtful. “You won’t bite the hand that feeds you” Definitely a conflict of interest.

ADHC is absolutely hopeless in answering complaints about a service providers policies. They will no get involved and neither will your case manager. There is no effective complaints systems regarding service providers and service providers do hold their authority and can place very restrictive policies upon you There needs to be one national policy for services and this should over ride the service providers. Service providers have enormous influence and power and they know there is very little anyone will do if you find their policies inappropriate

- **We need clear information about service providers policies before accepting the service.**
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- At present, you apply for a flexible respite package, knowing nothing about what the package can offer. None of these details are made available on the application form. Once you are lucky to receive it then are you presented with all the service provider’s policies and restrictions. At this stage it is too late to reject the package as there is no other packages available because they have all been allocated. There is a tremendous shortage of flexible respite packages.

You are then stuck with a service that does not really work for you. Service providers generally work well for individuals with low to moderate disability but when you start entering the realms of profound intellectual disability with behaviours, service providers don’t like getting their “fingers sticky “ with contentious issues and can be very inflexible in meeting the client’s needs. It’s all about liability.

One service provider dealing with flexible respite packages changed their criteria from one year to the next without advising of this in their application form. So when you applied for the package the following year you would reasonable assume you will be receiving the same service only to find out later that this would not be true. This service provider changed their policies for that year to include:

- no brokering out for staff
- no swimming allowed in backyard pools
- for the community worker to use their vehicle – no negotiation allowed anymore to use client’s vehicle
- limited km’s

there were more changes but I won’t go into them

These restrictions impacted on the flexibility to use the package. Firstly, a new staff member had to be trained to manage my daughter’s behaviour and that took up the first two allocations of respite. After all this, this staff member could not connect with my daughter . I eventually found another worker

My daughter's only obsession is swimming so this restriction severely impacted on her activities by not being able to use the backyard pool. The service provider considered she could drown. My daughter is water safe and competent in the water. The community worker will be in the water with her. My daughter does not have epilepsy. The risk of my daughter drowning would be the same for the population at large. A freak accident.

However, another service provider in the area allows swimming in backyard pools subject to some conditions being met.

The policy not to use my motor vehicle meant me paying huge amounts on km's because by daughter loves driving (thus reducing my monetary value of my package). Managed to get limited km's changed.

What then happened - one particular day the community worker could not attend a designated shift and I wanted the shift to be brokered out to an agent that has staff to trained to deal with my daughter (previously worked with my daughter). This service provider would not allow this and insisted I accept another community support worker of their choice employed with their organisation – this worker had never met my daughter. I was reluctant but accepted because I required respite on that particular day for an appointment.

When I got home I went through my contract and saw there was provision for the service provider to broker out. I investigated this and only then discovered that the service provider had cancelled their contract with the broker but never advised the client or stated this in their contract. It was their opinion that they would only broker out if another "suitable" worker from their organisation could not be found. I presented to them that a perfect stranger to my daughter and in my home, given my daughter severe behaviours is not "suitable" to me. To cut a long story short they eventually conceded and brokered out to another service provider that runs programmes that my daughter participates in and therefore community support workers that are familiar with her.

I time and energy spent on this should not have occurred. Why not just broker out in the first place. If it assists in making the respite a positive experience for all then it's a gain. Their was on $4 per hour difference in cost and if I wanted to accept that whey should any service provider insist otherwise.

My council area inhabits a population of 247,000 and there are only approx 60 flexible respite packages (2 service providers) for the area on a per annum basis. Not a great choice!!!!

- **Excessive paperwork and filling in forms every year.** Reapplying for the same service every year requires all the forms to be filled in all over again.

- **Community support workers to be more flexible in employing**. Similar to a registered nurse or school teacher. Once an accreditation has been obtained a nurse or teacher can work in any school or hospital, either on a permanent or casual basis without registering with an agent. The community support worker to have a registration number. This will enable a service provider to access a nominated worker directly (say a client requested a particular worker on a casual basis of a couple hours on a Sunday) rather than brokering out to an agent or to another service provider where the worker in currently permanently employed. A one page employment declaration to be filled in like any other organisation and the person's personal details. All other details should be on file according to their registration. This is particularly important when dealing with individuals with high support needs and behaviours. Very few staff are able to manage these individuals.

- If a client wished to hire a support worker privately, there is no workers compensation that the family can access should the worker get injured..
  Can a national workers compensation be available for families wishing to employ workers privately???.

- **You are your child's greatest advocate.**

- **We require more specialist accommodation for individuals with extremely low functioning autism** which is usually always accompanied with very challenging /complex behaviours.

  Regrettable the 24 nights of respite currently received is pathetic when you are caring for an individual with such high support needs that limits your everyday life severely. The strain and stress it place on family is enormous. At least 72 nights of overnight respite is required otherwise you will eventually relinquish care of your child and cost the government 4 times as much in supported accommodation, if your child is lucky to receive a permanent bed.

  What an inhumane way of dealing with the situation but there are families that can just not cope. They should not be expected to cope caring everyday with the exception of 24 nights per year.

  Last month I had a meeting with my local adhc office and requested at least 48 nights a year of overnight respite and was told I was being "overly optimistic". All I was requesting was the additional nights that I lost out on another respite house because that house only catered up to age 12.

Local ADHC is fully aware of at least 8 families that are in a similar situation to mine but there is no long term strategy of acquiring a home specifically for our children so we can have more over night respite. They will rather prop up the families with an extended family support package of up to $50,000 per annum to acquire additional overnight respite at a cost of $4,000 per 3 night weekend per person (2 staff per person) which will only last for 12 weeks and then what? They won't acquire a home for additional respite at a cost of approximately $330 per night assuming 5 children to 2 staff. There is a respite house in the inner south suburb of Sydney that is under accommodated. Approximately only 30 families access this home whereas in my local area of Sydney some 75 families access the respite house. But because you are out of area they will not access this home, except in extreme emergency. Why can't they use this home to accommodate for those families with children with behaviours until another solution comes up or the respite home is accessed by more families in the area.

They will then wait to see whether you relinquish care of your child in which case your child could either end up in a blocked respite bed, moved around from house to house or can either be put up in a motel room indefinitely.

Again, all these service are "crises" driven – definition of " crisis" not available but if you try to commit suicide, injure your child or walk out then you will be considered. Initially I did not qualify for the extended family support package because I "presented too well" and hid up my circumstances although I am known to my local adhc office and case manager that have all the details of my daughter's behaviour and situation.

The fact is that these extended family support packages have been made available to families caring for children with autism and severe complex and challenging behaviours knowingly that these families would be under severe stress and strain. In the ministerial press release there was no mention that you must be in "Crisis" situation – crisis is implied.

- I have been attempting to access the only other respite house in the area for the last 2 years but the service provider is of the opinion that my **daughter's needs are too high support to be accommodated for.** In the group of 5 that my daughter has been attempting trial stays with – 3 girls are low support with one girl so high functioning I did not know whether she was staff or a client. I thought that is what respite houses should be accommodating for – High support needs. Low support needs clients can easily be accommodated for with a host family. **The fact is the higher support needs your child is the more difficult it is to access services. Services you critically require.**

THE DRAFT REPORT ON NDIS RELEASED FEB 2011

- **Fully agree with the Law Council of Australia that funding of 12.5Bis insufficient** and may require three times that amount based on what NSW paid out last year -$38m for 390 claims for road accident victims resulting in severe disabilities
  See below on my calculations – very basic, rudimentary and estimates.

Supported Accommodation 36,000 @ $125 per annum = $4.5b

Day Option Programmes	250,000 @ $150 per day x 4 @ 48 weeks per year	=	$7.2b
Flexible Respite	250,000 @ $8K per year	=	$2.0b
Overnight Respite	250,000 @ $320 p/n @ 24 nights per year	=	$1.92b
Personal Hygiene and Care (just a guess)			$1.0b
Equipment and aids (just a guess)			$1.0b
Early Intervention and support	80,000 @ $20k per year	=	$1.6b
Additional Respite for complex Behaviours	20,000@ 50 additional nights @ $320 per night	=	$0.32b
Housing to accommodate 9,000 new homes for supported Accommodation (36,000 / 4 per home) @ $800,000 per home		=	$7.2b
Additional Respite Homes 100 @ $800,000		=	$0.8b
Assisstance with employment programmes			$?
Case Management, Advocacy and appeals			$?
Community access programmes, holiday camps, weekend Social groups etc			$?
TOTAL			$27.54

- **Supported Accommodation – your draft report does little to address the critical situation of supported accommodation.** This is our ultimate service that we require – eventually. Surely, when you have been caring for a child with severe/profound disabilities for many years, and the child is now a young adult, the carers should have the right to pass on care to the government so they can retire or regain their life at a time they choose. This needs to be a gradual and appropriate process with a home suited for their child within reasonable proximity to their family.

Furthermore this care should be offered on a permanent or permanent part time basis – what ever suits the family. The bed can be shared with another family if only on a permanent part time basis thus saving the government money. An example of this would include a family with a child with severe autism that has little connection with personal or materials things. The bed can me remade and room cleaned, items of interest can be locked away in a dual cupboard ready for the next client with severe autism to come in for their stay. To continue caring for a child with severe autism permanently and indefinitely is inhumane. You will be destroyed and your whole family too. The very least a permanent part time care would be ideal for a family that is still able to care for their child but not on a daily basis – say 4 nights with the family and 3 nights in care per week. (negotiable), or even say 4 nights a fortnight.

If only 10% of your 360,000 designated number require this service this alone will cost $4.5b (assuming a cost of $125k per annum per client on a 4-5 share basis). This does not include the capital cost of acquiring the homes – some multiple billion of dollars too.

This figure is not unrealistic. On FAHSIA website they quoted 1 in 10 people with a disability were in permanent care during the early 80's before they commenced relocating clients in homes. They now estimate only 1 in 40 people with a disability are in permanent care.

- **Simplify organisational structure –** hierarchies cost money. Do service providers provide any additional service over what government agencies provide?

- If there is **insufficient respite homes** and supported accommodation your funding allocation will not be able to "buy" overnight respite. If some families only required their funding allocation for 72 nights respite and there is insufficient homes to purchase these nights – the system fails. Be interesting what costing will be calculated per night!

- Whom and how is **"appropriate and adequate services determined**" For example – whom determines when I can receive supported accommodation for my daughter or substantially more overnight respite.

- We require **post school options day care –** like afterschool care but for individuals over the age of 18. For parents lucky enough to secure a part time job that abruptly is threatened when your child with a disability leaves school because there is no after "day programme" care.

- You stated on page 43 of your summary of your draft report, top paragraph, that individuals with challenging and **complex behaviours may have limited services** as service providers may not want to enter this area. **Please,** do not leave us out again and limit our services. Their must be some way of ensuring we will still have a choice in the services we require and the availability of such.

THANKYOU