

26 June 2008

Narelle

Secretary

Inquiry into Better Support for Carers

Standing Committee on Family, Community, Housing and Youth

PO Box 6021

House of Representatives

Parliament House

CANBERRA ACT 2600

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am a mother of two children with disabilities, my daughter is an 11 year old Autistic Spectrum Disorder and Intellectually Impaired person, and my youngest son is an Autistic person that will possibly receive a diagnosis of Intellectually Impaired as well due to his low scoring on a recent cognitive test. I run a support group for parents and carers of children with disabilities and I am the Secretary of the Lockyer District Concerned Parents of the Disabled Group Inc. I also participate in society as a full time university student and I intend to work as an environmental scientist next year, providing care can be found for my daughter.

Some of the problems my family faces include, day care for my daughter for both before/after school care and vacation care for next year, as most day cares only cater for children up to primary school age. Accessing relevant information for our family and for the families that attend the support group is a time consuming and difficult task. Accessing services such as paediatrician, speech therapist etc as Gatton is viewed as being too far out for these people and the time and costs of travelling to and from either Toowoomba and or Ipswich is very draining on a family in our situation. Toowoomba is closer but it is impossible to pull up on the range to attend to Jeffrey's needs in the back of the car and therefore this is a more difficult option. A further problem our

family faces is the constant battle to find appropriate schooling for our children. They are not capable of learning in a mainstream environment and they need a greater focus on life skills than children in a mainstream classroom, this is our personal greatest concern and with our youngest looking at prep next year we are terrified of him running out on the road and being killed. Having said this, the special schools are located at either Toowoomba or Ipswich and this is too far for our children to travel on a daily basis.

Finding appropriate housing is impossible for our children and you cannot alter rental homes nor can we wait for public housing (we are on the waiting list but will not be eligible next year if I manage to pull off going to work). For four years my husband and I had to provide 24hour around the clock care to our son, one of us had to be awake at all times and we had no assistance, why you might ask because we are privately renting and could not find a house that was safe enough for him when he woke up at night, we could not risk him drinking poison or getting out onto the road before we heard him. We had to maintain constant supervision and as he only slept approximately 4 to 5 hours in every 24 hours and as this was broken into chunks we could not risk not waking up in time. Therefore no private rental was safe enough and we could not access housing commission fast enough and we could not afford to borrow from a bank we had no option but to live four years of hell trying to run a home, keep up with two other children and provide 24hour care. No one could possibly imagine the strain that was place on our health and well being, our marriage, our family and our sanity and this could have easily been solved with full security screens to keep him inside at night, lockable cupboards for poisons and medicines and a small motion sensor alarm to wake us. None of which we could install in a private rental. We still face a number of safety issues in our home and we still get far less sleep than we should for our personal health and well being and we still need to have a safer housing situation for our son but thankfully we are coming out of it as he now sleeps an average of 6 hours a day and that 6 hours is almost in one chunk.

As a family we cannot access a lot of things in the community. For instance the circus is in town and that would be a lovely outing but it would be unsafe to take Jeffrey therefore one of us has to stay home with him and the other one take the older two children. We cannot go to the show, the theme parks, the zoo or the movies as a family unit nor can we go out to dinner as a family unit. This is mainly due to the lack of understanding in the community and the fact that we as parents are sick and tired of being told all our naughty boy needs is a good smack. We also do not access a lot of services provided for carers due to the requirement of filling out forms, I often wonder if those that design the forms have ever considered how they would feel as parents if they had to fill them out. Let me tell you most parents of children with disabilities feel depressed after each form they have to fill out and most attribute bouts or relapses into depression to the constant need to fill out such forms. These forms make you describe how difficult your life really is and that is something no carer needs to do every time they need help or to access a service.

Some suggestions:

Carer Housing Loans	Low interest home loans provided by the government to assist carers to appropriately house those they care for or to alter their existing home to make it safe and liveable, these home loans need to be available to all carers especially those that are unable to access home loans through banks etc
Community Education	We need the community to understand that we are not bad parents that kids with ASD do not need a smack and they are not just naughty, this will help both us as carers and our children to access things in our community
A One Form Wonder System	Where carers can fill out the one form and then just authorise service providers etc to access that information to assess eligibility to the newly requested service or assistance
Information Registry	Some place we can phone or email and ask where do we go for help with this problem/issue or who can come and help us with this
Day Care	Not family day care but centres that are able to deal with kids with disabilities including those that are attending high school
Services For The Forgotten Valley	We need services here in the Lockyer Valley and we need greater funding to encourage service providers to leave the comfort of the city and live in Gatton and other rural areas. One great example is the difficulty that the Lockyer District Concerned Parents of the Disabled Group had in getting an O.T. out here the typical response is 'I am not going all the way out there when I can get the same money here in Brisbane'
Special Education	We need greater recognition of the role played by both special education units and special schools and we need more special schools as these kids are not capable of travelling great distances. Increased access to special schools: Child has a diagnosable disability and cannot speak or still uses some babble Child has a diagnosable disability and is not fully toilet trained Child has a diagnosable disability and is likely to run away and run in front of cars etc. In other words access to special schools needs to be based on a needs basis and this would help minimise the amount of suffering from bullying these poor kids have to endure. This would greatly decrease my stress as a carer.
Re-Education of Mainstream Teachers	They need a better understanding of what parents go through and that it is not the parents fault and that the kids are not just naughty they really need to understand that statements like 'while she is in my class she will act normal and do the same work as all the other kids' or 'if you would do your job as a parent my job as a teacher would be easier and your daughter would learn' are just ludicrous, unfounded and lead to carers suffering depression and anxiety over taking their kids to school and picking them up. I still hate to do both!

Support for Support Groups	Somewhere that people can get ideas from and access information on who can come and give small talks to us also the availability of a small fund that would assist support groups to pay for the use of rooms and where necessary insurance.
Workshops	Carers need to be offered more workshops my husband and I attended our first one ever this week and it was so informative and useful, if more workshops were offered to parents then they would be have more confidence in what they are doing and a great opportunity to network, a greater understanding of what is out there and who can help them and learn coping strategies and how to help the person they are caring for.
Child Health Days/ Carer Health Days	There needs to be provision for Carers to take extra days off work to attend IEP meetings, Child specialist appointments etc, these are things carers must do and things that prevent them from gaining full employment as the need for such things are not recognised and this could be easily overcome through a government initiative that will allow for all carers to be given extra time off work to fulfil their carer role responsibilities, introduction of a carer day certificate similar to a doctors certificate but can be filled out by schools, therapists etc
Day centres	If you want carers to be able to work full time they need somewhere they can send the person they care for during the hours they work. Not all will need this but those that care for high needs disabled people that cannot be left unattended for 9 hours a day. These day centres need to be able to care for the person and to make their time there enjoyable and fulfilling, through the provision of meaningful activities, friendships and social events. This could be easily provided by providing funding to hospitals to build a small respite/day centre or to community organisations such as ALARA. This would reduce the amount of carers that are unable to actively participate in the community due to their caring role.
Fuel Allowance	Carers need a fuel or travel allowance to assist them with the additional costs they face in providing care to people with disabilities. This would probably be beneficial as a fuel discount card that provides x% discount on fuel.
Phone allowance	Carers that receive carer allowance should be entitled to the phone allowance and internet allowance as we need to make a large amount of phone calls for our children and we need the internet for information and to assist with accessing services as increasingly there is a move to online access.
Health Fund Specialist Gap Fees	The gap between what specialists charge us and what medicare pays is often unaffordable and there needs to be a way of assisting carers to access these important services perhaps a health fund specialist gap fee for carers only? Or a no gap fee from medicare for carers only??

The reason I have suggested the Carers housing loan is that we do not want to just be given things but we do have extra needs that make it difficult to work, extra expenses making it difficult to save and other barriers to buying our own home but we are not able to alter rentals to prevent our son from escaping, adding high cupboards or locking cupboards (plastic child locks don't work he breaks them in seconds) to prevent him drinking poisons, overdosing on medications as he simply loves them etc. So to keep Jeffrey safe is an exhausting job that could easily be rectified if we owned our own home but as we are carers we do not meet the banks criteria and we are not the only ones that are in this situation. Also others may own their own home but require modification they could borrow to have these modifications done and repay the loan. Both options would assist reduce carers stress and enable a safer and more liveable environment for the disabled person. This may also be an option for those requiring modification to vehicles or to purchase a vehicle because they are now caring for someone in a wheel chair etc. Or to purchase required equipment such as a wheelchair or a lift to get the person in or out of bed, the car etc. As carer's would be required to repay the amount this would reduce abuse and it would increase the carers self esteem or feelings of independence.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing the recommendations you make in order to improve support for carers.

Yours Sincerely



Narelle