

The Chair
Standing Committee on Health, Community and Social Services
Legislative Assembly for the Australian Capital Territory
London Circuit
Canberra ACT 2600
20 March 2010

Dear Committee Chair,

The daily care needs of a person with a disability can vary greatly but they are all similar in one way and that is the huge demand they place on the people who care for them. The job of caring is not just the physical job of dressing, feeding, toileting, bathing, administering medication, aiding movements from one place to another etc. etc. it is, especially for parents, an emotional minefield.

In order for parents/carers to survive emotionally and physically carers need time to care for themselves. They need regular, reliable and safe respite in order to recharge their batteries, plan and steel themselves for the continuing job ahead.

The respite available in the ACT is limited and does not suitably cater to the individual needs of the people it is supposed to service.

My husband and I care for our 14 year old daughter who has global developmental delay, mild cerebral palsy, epilepsy, an anxiety disorder and related behavioural problems which include self harm and lashing out at those around her including her 4 year old sister. We are constantly on the ready to deal with my daughters needs and to intervene for her safety and sometimes for the safety of others. It is exhausting! As a family we desperately need respite from this situation. We have no family or friends who are able to give us break

We have looked at and applied for various respite situations and the following are the issues we have had with each place that offers respite.

1 Tandem:

- a. Tandem provides in home respite – for reasons you will see below it has really been the only respite option we felt was safe for our daughter. We were given an allocation of 6 hours per week. We used to use 5 hours on the weekend, when our daughter would be cared for at home while we did shopping or took our younger daughter out and gave her some time with her parents when we could actually concentrate on her and do things with her that we couldn't do with her sister around.
- b. In September 2009 Tandem reduced their weekend hours and said that we could only use 4 hours a fortnight on weekends and had to use the other hours during the week. My husband works during the week so we can't spend time together if we use respite during the week –when you are caring for a child with special needs you need to spend time with your spouse otherwise you have no relationship at all and are going to wind up getting divorced.
- c. When I requested respite during the week Tandem was unable to provide it at the times I needed it because of staffing issues.

- d. Staffing issues are another big problem with this form of respite. People are employed part time and are usually Uni students who work for a few months or years and then leave. My daughter has had about 15 to 20 different carers in the last 8 years. This is not healthy mentally for us or our daughter. It means we have to keep “training” new carers and it also exposes my daughter to way too many people who are taking care of her personal needs which reduces her ability to protect herself from abuse as the concept of “stranger” has no meaning anymore.
 - e. Tandem needs to employ full time dedicated and well trained staff specifically for the job of caring.
2. Hartley House: We looked at Hartley House for occasional respite for our daughter but she is not in a wheelchair and all their other clients are. They are not set up to care for mobile people and would have to leave my daughter alone while bathing other residents, which is not an option as she can’t be left alone. Her anxiety disorder means she is terrified to be left alone, if I am home alone with her I can’t even go to the toilet without her having to come with me.
3. Teen House: Up until now we have not been able to access Kese or Teen house because of the following reasons:
 - a. Sexual Health & Family Planning ACT (SHFPACT) have statistics saying that 70% of children with special needs have been sexually abused by the time they are 18. The reason given for this is because disabled kids are “touched” for toileting; physical care etc. by so many people, carers, LSA’s, teachers, parents, doctors, nurses etc. that they lose their natural ability to feel uncomfortable about certain people and to say no. Also they can’t fight back or speak out.
 - b. To help our daughter maintain some self awareness and personal physical safety we have made it a strict rule for both our daughters that NO Males except for their father are to take them to the toilet or bath them.
 - c. Teen and Kese only have one worker staying overnight with 6 children.
 - d. Most of their workers are male – both places, at the time I applied, could only offer 2 non consecutive nights a month when they had a female worker on duty and we were warned the worker could cancel at very short notice and then we would have to collect our daughter at a moment’s notice.
 - e. Most paedophiles are male and most have no criminal record yet and they place themselves in situations where they have access to children – what better access than being left alone overnight with 6 kids who are unable to fend for themselves and better still can’t accurately report what is happening to them.
 - f. If there was an emergency 1 staff member could not help 6 disabled kids.
 - g. For that one staff member it wouldn’t be safe either, if an allegation of abuse was made even if it was never proven and was totally false the staff members reputation tarnished.
 - h. Needless to say we have not seen these places as safe for our daughter.

A far as we know there are no other options.

When our daughter is an adult and we are older and we are less able to care for her the need for respite will grow substantially.

My health and my husband's health are deteriorating rapidly due to the physical and emotional stress we are under with our daughter and we need more respite urgently.

Families need Regular, Reliable, Safe Respite and lots of it URGENTLY.

Yours Sincerely

Parent