

Respite Enquire Submission

I am the parent of a severely disabled Child, aged 10. My daughter, since two months old, suffers from developmental delay, and epilepsy. She is unable to do anything for herself and depends on others for care. This includes feeding, toileting and bathing, and positioning her for sitting or lying down. She is unable to move, sit or walk (wheelchair bound) and cannot communicate. My husband and I have been looking after her and we receive a limited amount of respite support. Which most of the time is not used because of illness or seizures or we are just too tired. (our respite is evening based).

I went back to work only because the Belconnen Community Service provided me with Child Care in a wonderful centre for my daughter. She now attends school at Cranleigh Primary and with the Belconnen Community Services continued support providing after school care (in a safe environment with a resource worker) and family support is the only reason that I can work 4 full days and one part time day.

My concerns:

AFTER SCHOOL CARE.

After school care when she moves into **High School** will be the next immediate issue for me. As I will not be able to access after school care due to government rules/policies on age of children. Do I give her a key and ask the bus to leave her at the front door to let herself in? Impossible. more likely my husband or I will need to cut back on our hours of work and the impact on financial side of our life could be dramatic.

Please look at the providing respite services for working parents – after school care at any age whether if be through more respite hours or a facility to which teenagers can be drop of as end of school and pick at after work hours.

RESPITE SERVICES

I have never accessed respite services other than in my own home through Tandem (Fabric).

I want to point out that I don't know where to access respite which is suitable for my daughter and her high complex needs. There is no information that is easily obtainable on high level respite services.

I have heard stories from other parents that some respite houses are understaffed, and some children have behavioral problems that can put other children at risk. I am not about to place my daughter in danger as she is unable to defend herself or communicate her needs, anger or frustration.

I hope that someone will address the lack of respite for high level needs children/teenagers which requiring one on one care. Where are we to place our

children as it becomes too hard for parents to care for them at home or just need a break?

Currently I do not plan ahead for anything and my son is missing out on events and doing things that are just normal, going to the park, beach or parties. Being a family with severely disabled child and having to ensure her safety and health over other things can be very stressful and tiring. Trying to get a balance, to ensure my sons' needs are met is hard.