To whom it may concern

I apologise for the lateness of this response to the current enquiry into respite care services within the ACT.

Background:
I am the parent of a severely disabled 14 year old. My son, since birth suffers from severe low muscle tone and epilepsy. He is unable to do anything for himself and depends on all others for his care. This includes feeding, toileting, and all other aspects of personal care. He is wheel chair bound, unable to sit or walk and also has limited ability to communicate. My husband and I have been looking after him since his birth and for the first five years of his life, this was without any respite support.

During the early years of his life it was so difficult for us without respite support (nor any family support) that I took two years off work from my Public Service job and since his birth in 1995 up until today only work part-time.

When I needed to go back to work (1997) I could not get respite care through TANDEM (formerly FaBRIC) because they only offered respite care for short periods of time and only for "recreational" purposes such as allowing me to go shopping or have my hair cut. We ended up advertising in the newspaper for carers. This carried its own risks (police checks etc could not be enforced) and after meeting and "trialling" the carers I got through this exercise, we abandoned the whole idea.

Around that time, FaBRIC changed their policy to providing respite support to assist with me going to work. Under their assessment process we were allocated a maximum of 10 hours of respite care a week. (This 10 hour allocation has remained at this level up until today). Based on this policy change, I was able to resume my job but for only two days a week while care was provided at home. Again, this carried its own risks and I had a series of awful incidences such as carers not bothering to turn up (and failing to let me know), having to accept whoever I was offered (because carer shortages have always been a problem - resulting in desperate situations for families like ours having to either accept a carer who is less than ideal or forfeit care.

When my son turned 7 years old in 2002 (and after the birth of another child in 2001), he was strong enough to start school but only for 4 days a week and to this day he attends school for 4 days a week only given his physical capability and the fact that he tires very easily.

Currently
Since my son started attending school in 2002, I have been able to resume work 4 days a week and a life of relative "normalcy". However I work school times i.e. 9.30-2.30 because I have learnt over the years **not to rely on respite care as means of maintaining other aspects of my life, such as my job**. This is because history has well and truly demonstrated the following issues:

- A chronic and consistent lack of carers in the respite service industry - there are waiting lists for respite care and we are **again** currently on that list and sharing it with 13 other families. Inexperience seems to be a major issue, high staff turnover - perhaps because of the lack of appropriate pay paid to carers?

- When I have had good carers, invariably circumstances change and we are left without support.

- Often we are given no notice that a carer is not going to continue to provide care - this happened to us just last week where the carer failed to let me know that she had applied for full-time study at university and had been accepted. I found out after the event and off-course, after I had planned important things to do during these periods of respite. In addition, I was not given an opportunity to have someone else trained by this carer before she left - leaving me and my family back at square one.

- I have consistently had care cancelled an hour or so before care is supposed to be provided and yet, TANDEM's current policy is that if a family no longer requires care then the family has to let the respite service know 24 hours in advance otherwise we are charged for an hour of service we did not receive.

- I have consistently been offered replacement support where my children and I have not even had an opportunity to meet and know the carer - naturally I have always declined.

- Although allocated 10 hours of care a week, due to the chronic lack of respite carers available, we have, on average only maximised 6 hours per week of care - for me to go to work.

- I have been told that care extending to other siblings is not a "right" but a privilege - not sure if this is correct or current policy? However it did lead to an absurd situation in earlier years where I asked for respite care for the sibling of my disabled son so that I could take my disabled son for hydrotherapy. At the time, I was told that respite services were only available to the disabled child and that I would have to take the sibling with me if I wanted the support. What this meant was I dragged a sleeping baby (sibling) to a hydrotherapy pool with a carer and myself so that I could provide therapy for my son and have respite care to look after the sibling while I was there rather than having the carer at home with the baby!. Respite support actually made the situation a whole lot worse! A current example is my former carer focused solely on my disabled child and was excellent with him but completely ignored my other child (who is only 9 years old)

- Respite services are means tested. We are currently on the top of the pay range and pay $8.50 an hour for respite care. What is not factored into this equation at all is the opportunity costs foregone of me working full time over the last 14 years. In addition, what is not factored into this equation are all the extra costs including future costs of the care of looking after my severely disabled child including the high cost of equipment and home modifications as well as the daily costs of care.

- My son will turn 15 years old this year and in a few years time finish high school. Where does this leave me in terms of my ability to work? If I can barely utilise 6 hours of respite care a week when he is in school what will I be able to do when he finishes school??

These are only *some* of the issues I have dealt with over the years and continue to deal with. "Respite" is supposed to make things easier for families. You can see that the current system has its dire failings.

I would be more than happy to provide additional detail should you wish to follow up any aspect of this email with me.