

Submission  
No 13

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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Thank you for this opportunity to contribute to this inquiry.

Firstly, I should state that I am the mother of a 17yr old boy with severe/profound intellectual disability. My son is totally dependent and requires care 24 hours a day, 7days a week. He is non-verbal, incontinent, unsteady on his feet, requires full assistance with personal hygiene, dressing, feeding etc... Yet, he is still mobile and this presents it's own set of problems. He has no sense of danger, personal space, social boundaries etc... He is a potential danger to himself and others. I feel this small minority population, at the extreme end of the spectrum of intellectual disability have had their needs totally bypassed by mainstream service providers, including disability advocate groups.

I have been very fortunate to find suitable services for my son provided by church charities and small community NGOs. I say fortunate because I have found ADHC (DADHC in a previous life) to be totally and depressingly inadequate in almost all respects. I am not alone in this opinion. This opinion is shared by every NSW parent I have ever met who is caring for a child of similar needs.

In 17 years I have seen no progress or change. This is particularly depressing as church groups, one by one, are closing services in an industry that can no longer be run by charities due to increasing costs caused by increasing red tape and accountability/legal/insurance requirements. As my son turns 18 years old, I find myself faced with few options other than ADHC services. I have been dreading having to deal again with this inefficient, dysfunctional and totally exasperating department.

As my son nears the end of school years, I have been reintroduced to the saga of the ADHC caseworker. Since the begining of this year I have attended 3 meetings with ADHC representatives and I am yet to see the same person twice. On seperate occasions I have spoken to 3 different people who have introduced themselves as my sons new caseworker. I have spent 2 hours with one of these caseworkers providing a profile of my sons needs post school. I have never spoken to the same person twice. The last person who introduce themselves a our caseworker said she would return to us with progress updates, that must have been about 2 months ago. I know I should have followed her up, but I also know that she has probably been replaced by a new person and we will just have the same conversation over again. ADHC seems to play a continual game of musical chairs and it is near impossible to have more than 2 conversations with one person before they have moved on and a new person has taken over their position. Dealing with ADHC is like living the movie GROUNDHOG DAY, except it doesn't get better, it just gets worse.

15 years ago the services offered by ADHC were inadequate for my son's severe needs. The names have changed, there have been flashy launches of new programmes with catchy titles like STRONGER TOGETHER, but at the end of the day they are still offering the same inadequate services they were offering 15 years ago. No change, no progress.

Sure the budget has increased, but demand has increased beyond any budget increases.

Where are all the new supported accomodation places that government perodically announce???

How can I hand my son over to respite services where staff come and go in 8 hour shifts, and you can go weeks before seeing the same support worker twice? He has the intellect of a 9 month old baby. He is completely nonverbal with no communication skills. How can someone who sees him once in a blue moon understand what he is wanting or needing. How can I feel anything other than guilty for being desperate enough to use these services. This was my experience with ADHC respite services 15 years ago, and I'm told nothing has changed. My information sources are varied and reliable, including parents and ADHC service providers.

How do I feel when I consider that after my son turns 18, I will be relying on ADHC services? I feel hopeless, depressed and exhausted.