

Submission  
No 71

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

Name: Name suppressed  
Date received: 6/08/2010

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Partially Confidential

Hello, My Name Is \_\_\_\_\_, I am 32 years old, Married with 2 young daughters',

For the past Approx. 3 years, my youngest child \_\_\_\_\_, has been a client of ADHC (Formerly \_\_\_\_\_ branch, currently \_\_\_\_\_ branch).

Im \_\_\_\_\_ Full-time Carer.

\_\_\_\_\_ has been diagnosed with A Unique, Un-diagnosed Syndrome, with her chromosomes having an abnormal 1P- (minus) deletion, & Translocation of her 11Q+(plus), floppy-Airways, For which she has a Trachistomy (from the age of 8 weeks old), She is fed Through her Gastrostomy PEG, Via A Kangaroo Pump, She suffers epilepsy (she has fits daily From as little as 3 a day up to 18 a day), She is Totally Immobile, (In a wheelchair & A standing frame), Suffers Incontinence (Approx. 10 nappies are changed daily), is on a massive cocktail of Drugs, 3 of which are predominately used to abort her seizure activity, for which we may never have full control of), she was born with a VSD & an ASD in her heart, she is partially deaf (her left ear), She is Globally/Mentally Delayed & Physically challenged, she can't even roll, sit-up, crawl or hold her head up un-assisted, she suffers from chronic lung disease, & has nearly lost her fight for life many times in her short life from contracting pneumonia & has had Renal stones in the past, which she now has scarred kidneys.

Basically, \_\_\_\_\_ requires 24/7 specialized care, & we have to guard her health from environmental elements (Wind, Rain, debris like sand, hair ETC from being inhaled through her Trachie and into her lungs, as well as safeguarding her from catching cold & Flu as best as we can). Even Bathing/showering her is risky as she could accidently splash/inhale water down her trachie.

Basically I adore my child, & as hard as it is to have given up my life & career, & other relationships & interests, and as complex as her health is, Im happily devoted to her life & well-being (for both my children).

For the first 2 & a bit years of her life, I basically had no sleep, I was suffering sleep-deprivation, depression, anxiety & from feeling isolated. I had no emotional or physical support from family or friends (Im originally from \_\_\_\_\_, so all my family/friends were back home), I had another child who was 2yrs old at the time, that I was also caring for alone as my husband had to work long hours to keep up with the cost of \_\_\_\_\_ medical supplies & to keep a roof over our heads & food on the table.

Not long after the initial first 2 years, \_\_\_\_\_ happened to be in respite care, when I fell terribly ill.

Not only did I have some sort of flu, but I think at the time I must've been going through a breakdown. I physically couldn't get out of bed, my husband wasn't coping with \_\_\_\_\_ prognosis, we were constantly fighting, & I was so tired.

I literally couldn't pick my child up from respite care, ans so the threats to my childs welfare began.

DOCS became involved, after ADHC \_\_\_\_\_ threatened me with Relinquishing \_\_\_\_\_ to Docs, which was not the case at all.

We were a family in crises & in desperate need of support for our childs care needs.

Basically all I need to say is that ADHC \_\_\_\_\_ have never been supportive of my & my child's life, we are constantly lied to, their so called services are never attending our needs, there is red tape on just about anything you can think of. I have never felt so demeaned as I have by my case workers & their management, I have never been promised things & lied to as much as they have to me & my family, I have tried everything, from aquirng an advocate to involving my local MP's, MP's in canberra, I have even welcomed ADHC to install cameras in my home, to see what's it's really like being tied down to one child in need, & how bad my situation is in terms of even doing "normal" things that most families take for granted.

Im not giving you a sob story here, I just want to put it out there, that in australia approx. 2.5 Million Aussies are battling the same issues as my family is, some worse off & some much milder than our case.

I just Think that ADHC \_\_\_\_\_ took a very cold-hearted approach to our lives, and have caused me and my family so much more pain & suffering than almost watching my little girl suffering, didn't they think it was enough that My baby girl was sick?.

I so sincerely want your department to please investigate the going-on's & intentions of certain individuals at ADHC \_\_\_\_\_, I think they should be interrogated Just as they had me Interrogated by DoCs, and I also would like to question my privacy right's via this Department (ADHC \_\_\_\_\_), & what they can & can't do without my knowledge &/or permission.

I will upload files below stating past & present issues with ADHC \_\_\_\_\_, ADHC funded service : \_\_\_\_\_ (nursing), incident's that've have happened to my child at \_\_\_\_\_ Respite centre

(also ADHC funded), and In-home domestic care (also Funded By ADHC), I will fax them instead if I cannot upload them.

But, Frankly the Disability system as it currently stands, Is Inadequate, dysfunctional & utterly failing to meet the needs of our little suffering daughter.

Please I urge you, Please Listen to our families cry for help.

Sincerely Yours,