

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

Name: Name suppressed
Date received: 5/08/2010

Partially Confidential

Submission to ADHC inquiry.

My name is _____, I live with my husband _____ and three sons, my youngest son _____ has a severe intellectual disability.

Respite

We made several attempts over the years to access ADHC respite however there was never a suitable place for him where _____ would be kept safe. No service met _____ needs in terms of him absconding, at one stage he absconded and was found at 3am wondering the streets, he has no concept of safety or indeed road safety so it was decided that we would, in _____ best interests, forego respite. One of the facilities was akin to a Dickensian institution and I felt enormous guilt sending _____ there anyway. This has meant we have been unable to have much needed breaks away from the caring role and this has taken an enormous toll on our health as individuals and as a family.

We seem to have found a respite unit now that looks like it will be appropriate for _____.

Day Program

_____ finished school the year the state government reduced the age of leaving from 21 to 18 so _____ finished school at 18 and was offered 3 hours per week of a day program. Already struggling without respite, I was very concerned about our ability to continue caring for _____ without any break at all. After much exhausting battling for increased hours _____ was finally given a day program 5 days per week. I objected to the fact that I had to more or less say that I would not be able to continue in my caring role in order for _____ to be given access to an adequate day program. These services should have been available to all school leavers with a severe disability.

Transport

Transport is an issue for many parents, at one stage I transported another young woman with a disability to and from her respite and day program as her mother does not own a vehicle, transport should be provided to and from day programs and respite. The lack of transport creates increased hardship for many families, particularly those than do not or cannot afford a vehicle.

Paperwork

The paperwork and constant repetitive questions I need to answer in order to access ADHC services have caused me great frustration and stress. I spoke to

another mother recently who said that she felt traumatised by having to re-live difficult experiences over and over again. There absolutely needs to be an acknowledgement of how much burden is placed onto already exhausted carers by asking them to repeat the same processes over and over. Isn't this what Caseworkers are supposed to be for?

Caseworker

The Casework service has been fraught with stress and frustration, more trouble than it's worth. We can never get in contact with our Caseworker and she often does not return calls until a week later, by the time she does the issue I needed her help with has passed. I find it much easier to deal directly with the respite unit as they have been much more helpful.

I feel the Caseworker patronises us and speaks to me like I am stupid, she has pressured us to fulfil her timeframe rather than what is best for [redacted] and our family. She has remarked that [redacted] transition to respite is the 'longest she has ever known' and I feel pressurised and stressed by her, it's clear we are just a number to her as opposed to trying to provide us with an individualised service as per the Disability Service Standards that ADHC are supposed to abide by. She seems quite focused on merely 'closing the referral' and meeting ADHC needs first.

There has been very little acknowledgement by the Caseworker that we are [redacted] parents and know him best. I am left totally baffled as to what the role of a Caseworker is, despite her stating that [redacted] is taking too long to transition we have only ever met her twice in person and she has only been to my home once.

I feel that the role of 'grief' is overstated when a parent/carer tries to stand up for their rights, any complaint or problem with ADHC seems to be met with a stock standard 'they are grieving', this has little relevance to most complaints made by families, many of which are legitimate and grounded in fact. The 'grief' issue prevents many families complaining about inadequate services as they are met with this response and their complaint is disregarded.

The Casework service needs close examination and questions need to be asked, important questions like – do Caseworkers cause more harm than good?