Submission No 26

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

Name:

Mrs Narelle Hughes

Date received:

4/08/2010

Inquiry into Services provided or funded by the Department of Aging, Disability and Home Care

I am the mother and carer for my 22 year old daughter, who has severe multiple disabilities.

In order to save me rewriting and explaining my situation again, I have attached a copy of an appeal I made to DADHC a few years ago, which explains my daughter's level of need and also highlights one of the many flaws within this Department. I have also attached a copy of part of a submission I made to the inquiry into Better Support for Carers which is also relevant to the points I wish to make in this submission.

I will not respond to all of the Terms of Reference, but hope my contribution regarding some of them is useful to this Committee.

- a. Hopefully this inquiry will be able to expose the extreme levels of unmet need and publicly announce their finding. The general public have anecdotal evidence of the desperate situations many families find themselves in, but the real numbers of people whose needs are not being met should be made clear.
- b. Having lived in both coastal and rural NSW as well as Sydney, my experience has been that services are lacking in all areas. Many of the service providers funded by ADHC have a commitment to their clients but are so overstretched due to lack of funding that they are unable to provide individualised programs. Services provided directly by ADHC are difficult to obtain, unreliable and seem to be more interested in administrative detail than the client. This is of course a generalisation, but those ADHC staff who try to do the best for their clients are usually stretched to the limit and 'burn-out' within a very short time.

The situation in regional areas is even worse, with the lack of allied health professionals and case managers employed directly by ADHC.

- c. There is very little flexibility in funding. The Department seem to believe that funding of large established organisation is best practice. In reality, they are funding organisations which and becoming more interested in their management structure and 'meetings' than they are in actually providing a service. Management in these organisations are making decisions which affect the lives of their clients without consulting them.
 - Funding must be individualised so that the client is given the power to decide which service provider suits their needs and only then will service standards improve. This also

impacts on situations such as that described in the attached Submission to the Inquiry into Better Support for Carers.

I believe that smaller, locally managed services are always going to provide a more personalised service to their clients especially if the clients have individualised funding.

d. ...

e. The attached appeal which I made to ADHC did fortunately end with an acceptable outcome. The question I put to this Committee is, why did that appeal ever need to be made? My daughter has been a client of ADHC (DADHC/DOCS) for over twenty years, and I have filled in many, many forms over those years. Where did all that information go? Commonsense was not evident and resulted in costs, time and stress for me, and unnecessary time being taken from doctors, teachers and other interested people, as well as the time of those on the appeals committee.

I would also advise that I have made complaints to an ADHC funded service provider and not been happy with the outcomes of that complaint process. When I took my complaint to the ADHC Management they replied that they have no authority to investigate the complaint...they only make sure that there is a complaint process in place.

f. I have been involved in the audit process of two ADHC funded services. I was invited by the service providers to represent my daughter as a service user with the ADHC auditors. This process was not difficult but my impression was that the auditors were overly interested as to my knowledge of the complaint process rather than whether the service provision was acceptable.

I also question the process which asks the service provider to invite the service users to be interviewed by the auditors. No service provider is going to invite someone who is not happy with their service. Surely ADHC should have records of who is using which service provider and then ADHC should decide who they interview. There is another service provider with whom I am not happy, but I will never be invited to their audit!

g. ...

Thank you again for the opportunity to express my views to this Committee. If you require any further information, do not hesitate to contact me.

Yours faithfully

NARELLE HUGHES