

Submission No. 896
(Inq into better support for carers)

From:
Sent: Friday, 4 July 2008 11:43 AM
To: Committee, FCHY (REPS)
Subject: FW: BETTER SUPPORT FOR CARERS

-----Original Message-----

From:
Sent: Friday, 4 July 2008 10:03 AM
To: Committee, Reps (REPS)
Cc:
Subject: BETTER SUPPORT FOR CARERS

Dear Chairperson.

Thankyou for the opportunity to comment on this important issue.

My wife and I are carers for our 19 year old daughter Ashleigh who suffered meningitis at age 6 months. Ash has never walked or talked has cerebal palsy and is profoundly deaf. Ash is also severely neurologically affected. She lives with us and as she is not at risk with us we do not receive any intensive family support funding from the state.

There is an extreme shortage in available funding despite her significant life long disabilities.

We currently receive Carers Allowance only and Ash receives a Disability Support Pension.

Our role is to care for Ashleigh and to identify and maximize her lifetime opportunities. We do this as her parents and as there are very few appropriate options. Our role is conducted in a very private way and to the extent of our abilities. Ashleigh has two sisters , one older and one younger who have assisted us but they are now young women with demands on their time. The question is where are we headed and who cares ?

Apart from all of us getting older Ashleighs needs are being compromised by a distinct lack of services to address them. As her carers we are continually having to manufacture her life pathway whereas our other children have choices along established and robust routes. As carers we witness the absolute need for extra adult therapy services for young adults such as Ash whose ability to live a healthy lifestyle depends on this – but cannot be readily sourced.

As carers we provide her accommodation willingly at home which we believe is the best place for her and is the appropriate style of accommodation and care given her unique circumstances. There is no recognition of our 24 hour

Role , no recognition of our provision of a safe environment , no assistance with a plan for her future.

We seek help with giving our critical role real recognition so that the collective carer work force remains intact. We endure more than most , deliver more than most and receive less than most for our efforts. The never ending demands of our role are not well understood generally and by decision makers which is a constant battle.

Delivering support services and planning for workforce assistance and encouraging in home / at home accommodation arrangements and providing encouragement and incentives for carers to keep doing it

Are just a few ideas we would find of value.

Our position is that the Commonwealth , State , Local Government and Carer Families all have a role to play. A team approach , a community approach . This is not evident today. Federally the tax system and Centrlink are available to provide meaningful incentives for carers , especially those who accommodate their family member and employers and employees who work in the paid care worker industry , for example . At state level care plans for households and robust service provision along the changing life pathway along with concessions on utilities and rates etc by local government. The family contributes the doing and accommodation as well.

A move by the Federal government to provide a recognition package for Carers through this enquiry would be a real plus for us all !!

Thanks again for this opportunity.

Bruce and Jenni

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