Submission No. 1028
(Inq into better support for carers)

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Gillian

3 July, 2008

Inquiry into better support for carers

Dear Sir or Madam:

My name is Gillian ; I am the wife of Peter , mother to Kyle, Aidan, and Alex, foster mother to David and Kristy. I work two jobs casual and I am the primary fulltime carer of my son Alex. Alex is fourteen years old. Alex is a happy young man with severe quadriplegic cerabel palsy, cortical visual impairment, epileptic and intellectual disability. Our two foster children David and Kristy have been assessed as having moderate intellectual disabilities.

I have just returned to work after eight years. When Alex was born I had to quit my nighttime waitressing because he was difficult to feed and was a distressed baby. My husband Peter found it difficult to care for him along with our other two young sons. When Alex was able to attend Havenlee School I found work as a teachers aide this worked well as I was able to be home for my children during the school holidays. The only difficulty I had was when I needed to leave work to care for Alex if school called, this happens more for Alex than my other children. In the late 90's my husband and I decided to become foster carers. In the year 2000 we agreed to care for two young children long term. To give Kristy and David the best care I left my perfect job. It has been eight years and I need to be apart of another world other than disabilities. David and Kristy need Occupational Therapy, Speech Therapy and the extra care that comes with a lack of understanding what we take for granted.

I want to work to contribute financially to my family as well as be apart of the wider community. I felt isolated, lonely and lacked motivation when my days were filled with appointments to doctors and health workers or being left at home to care. I still need to attend to the therapy needs of my children so a full time job is not suitable. I am trying to find a solution for after school care for Alex to cover the hour that I am finishing work and travelling home. Alex has never been in respite or home care; we have relied on family in emergencies. Peter's parents are in there seventies and mine are dead. I have contacted Interchange and dadhc but neither could help. My husband Peter has been leaving work early so that I am able to give my best at my new job at tafe but this will not be able to continue. If I am unable to find a solution I will have to quit my new job. I am also worried about my ability to work when Alex leaves school in four years. Peter and I have no intentions for Alex to leave our care we wish our son to remain in the family home for the rest of his life.

I hope I am also entitled to retain the carers allowance card as this gives my family access to the pharmaceutical benefits, which we need. I would like to be able to earn more and keep this as I became physically run down in January 2008 my immune system was low and I contracted a golden staff infection. This infection took six months, lots of anti-biotic and daily visits to my local doctor who thankfully bulk bills my family.

Alex needed to be away from school for the whole of the last term of 2007, I was not working at the time but this occurrence does happen and it affects my reliability and availability at work I am also a waitress at a local restaurant I am only able to do this because my husband is willing to care for Alex and David and Kristy on Friday and Saturday evenings. This type of work prevents socialising and weekend visits to family but I know my children are cared for in a safe and loving environment. I can bring in extra money that is needed.

I hope this letter helps. I would also like to say thankyou for the help with equipment and nappies from PADP the cost of these necessary items is extreme and I am grateful for the assistance.

Sincerely,

Gillian
Mother/ Carer