

ML 2/8/08

31/07/08

To Whom it May Concern:

Re: Better Support for Carers

I write in desperation to seek greater support for Carers – standing on the brink of the potential disintegration of our whole family.

I am the mother of a 20 year old son, Daniel, who is autistic. After 20 years of caring for him almost totally by ourselves, except for private services for which we have paid a fortune over the years (to little effect), our family is in crisis. My husband was diagnosed around 18 months ago with Parkinsons Disease, which we believe was largely brought on by the stress of living with Daniel. Our daughter suffered from anorexia nervosa a few years ago, also at least partly caused by the anxiety she suffered trying to protect her brother. In addition to caring for my loved ones, I have been battling over the last 18 months with caring for my mother with cancer, back in the UK and an invalid father. My mother sadly passed away at Christmas time, which has constantly taken me away from my family when they most needed me.

Daniel suffers from many of the extreme core deficits of autism. He lives in his own little world and has little power of rational thought. We struggle to get him to maintain any level of personal hygiene – although he will shower, he rarely shaves or washes his hair, he cuts his own hair (sometimes down to the scalp), he will not change his clothes. He refuses to go to the dentist or doctor or any other essential appointment. We managed to keep him within the school system until 18, attending special schools or classes within mainstream schools. Since that time he has not settled at any Transition to work programmes. He does not understand what they are and has been increasingly oppositional and defiant, rarely attending the programmes and instead becoming increasingly obsessed with his own little world of sitting at home, either playing cards, on a computer, listening to music or simply doing nothing. He is increasingly closing down and resisting any attempts to get him to socialize or go out. We have employed many, many carers to come around and try and engage him and get him out, but he now will see no one. His anxiety and depression has undoubtedly been worsened by my constant trips to the UK and his father's poor health. Our frustration and emotional torture has stretched our mental health to an extreme.

Our stress has been magnified over the last year because he has started stealing money from us whenever we leave wallets or handbags around, with which he buys endless DVDs and CDs. AND whenever we are out, he throws away anything of value, eg money, phones, cameras, DVDs, CDs, photos, home videos, clothing (including his entire

wardrobe of clothes!), while we were away recently, leaving himself with just 2 pairs of shorts, 2 T-shirts, one sloppy joe and 1 pair of socks. We have got to the stage where we dare not leave the house when he is there because we do not know what will happen next. We have just bought a safe to lock up our wallets and are having locks put on most room doors. We have had to lock away anything that is left that is of any value or sentimental value. We are prisoners in our own home.

We are at our nerves ends. We live our lives walking on eggshells, not knowing what will happen next. My husband's health has deteriorated rapidly, caused by the extreme anxiety and depression, with which we are living. He has reached a point where either he will leave our home or my son will have to. As the mother and wife in the middle, I am being torn apart.

SOLUTIONS

There is no simple single solution to help people with developmental and intellectual disabilities like autism. But the strain needs to be lifted from families or the whole family will collapse. Some suggestions are;

- Much more supported accommodation across all areas. Not just respite but full time care, which needs to be close to the young person's home. It is unreasonable to expect these young people to live a long way from family.
- Explore options for families and govt to work on joint accommodation solutions, where families are able to.
- More in home care. In cases like ours where our son will not leave home to go to respite care or to anything else, more trained carers are needed to live in the family home to allow parents to go away to keep their sanity.
- More freely available case workers to discuss options and give advice on a long term basis not just temporary.
- More psychologists or psychiatrists to help with hands on help for the young person and to provide parents with strategies and on going emotional support. (A major problem is the isolation that each family suffers)
- Availability of someone to talk to on the phone (Over the last 10 days I have tried to phone many people at DADHC to ask for some assistance. All I ever get are answering machines and I have only received 1 return call, which said that sometime over the next few weeks they will try to get someone to call us. We may not survive that long. Even someone to talk to would be a help.)
- Continuity of DADHC staff. The constant turnover renders most help from DADHC useless. Salaries or conditions or something needs to be changed. Also an end to the eternal re-structuring of DADHC would help, with some of that funding going to real services rather than changing letterhead AGAIN!

TIME IS OF THE ESSENCE! FAMILIES NEED HELP NOW! OR THE STATE'S BURDEN WILL GROW EXPONENTIALLY, AS THE PARENTS AS WELL AS THE CHILDREN END UP SEEKING HELP.

Janice