

## Testimony for Senate Field Committee Sept 7<sup>th</sup>, 2010, Milwaukee, Wisconsin

My name is Dorothy Williams. I live in Wauwatosa, Wisconsin, in Milwaukee County.

I have been asked to speak on behalf of family caregivers who have been recipients of services through the National Family Caregiver Support Program (NFCSP) in Milwaukee County funded by the Older American's Act and administered through the Family Caregiver Support Network (FCSN) at Interfaith Older Adult Programs, Inc.

I care full time in our home for my 101 year old mother, Margaret Dunn, who has senile dementia and who has lived with us for almost 9 years after walking out of her home and becoming lost one Sunday morning. With my husband's support, I feed her, look after her hygiene and her health care, administer and regulate medication, incorporate her into family and church life, and include her in social activity where appropriate.

Two years ago my mother broke her hip. Although her hip was successfully repaired, this contributed to a worsening of her dementia. I had to quit my job at that point to care for her full time. As she was being discharged from the rehab facility, I was asked whether I would like to meet with a Milwaukee County social worker about programs that might be available to us. I wasn't very optimistic, as I thought most aid was linked to income. My mother has a very modest amount saved up that would cover approximately one year of nursing home care. That, with her Social Security and modest pension made us ineligible for aid based on financial need. I agreed to meet anyway, and it was at this meeting that I first heard that federal funds were available for respite to family caregivers of family members with dementia/Alzheimer's through NFCSP in Milwaukee County funded by The Older Americans Act and administered through FCSN. **Here** was a fund that took nothing into account except the **need of the caregiver**.

Until that meeting, I had not given any thought to respite care for myself. Since my husband's retirement, we were on a tight budget. I had read the literature about care giving but I was sure I was functioning OK. The availability of this aid forced me to begin to care for myself. I went to the doctor. I saw friends. I had dates with my husband. I realized how drained I had become, and I began to take care of myself and not feel guilty about it.

Anyone who has cared for someone with dementia knows that you must always be friendly, always be patient, always be kind, never lose one's temper and never become irritable; in short, to exhibit a superhuman attitude. If I displayed any of those negative emotions, my mother would cry. Not a good thing. That bit of money made me realize how important respite care for caregivers of loved ones with dementia or any other disability really is.

Interfaith Older Adult Programs, Inc., which includes Pat Bruce and her staff at FCSN, was wisely chosen by Milwaukee County to administer the NFCSP funds. Pat Bruce and her staff at FCSN made the liaison with a local care giving agency easy. They have been a friendly, knowledgeable and patiently

encouraging resource. I have been most impressed with the integrity and creative stewardship of the funds they have been entrusted with. In a society where there is temptation to waste funds or misuse funds, or to act arrogant or powerful, Pat Bruce and her staff at FCSN seem to work miracles with modest resources, while helping families in Milwaukee County who are caring for their elders. I would strongly urge anyone who wants to improve elder care giving or dementia care or family care giving to have FCSN give advice on how to make a program work on the ground.

I was told that the respite fund was available for a limited time, which leads to an observation on the superiority of family care giving over institutional care. My mother has been with us for nine years. She interacts with our family, her relatives in the area who visit us, and those we visit with her. Even though her communication skills have declined, she is exposed to the many and varied events of family life. She is not confined with a population of other elderly persons suffering from dementia.

I believe that family care giving of elderly family members should be encouraged, as good for the elderly person, and much less costly than institutional care. There is a place for institutional care, but it is as a last resort, when dementia or Alzheimer's has reached a stage that is beyond what a family member is capable of handling, or when there are no family caregivers available. The dollars spent for family caregiver respite are a pittance compared to daily institutional costs.

I would urge you to please extend The Older Americans Act and continue to fund the National Family Caregiver Support Program. Please expand these programs to increase areas of service. Funding for this Act has only been modestly increased in past years. Please generously expend the funds to continue to help **more** families care for their loved ones. I would recommend that family caregivers be given more ongoing funds for respite as in Wisconsin's Alzheimer's Family Caregiver Support Program (AFCSP). Each year that dementia increases, the family caregiver needs more respite, not less.

There are thousands of family caregivers out there. Many families are keeping their loved ones off Medicaid. We are not earning a salary doing this. Family caregiver respite funds really make a difference in the quality of our lives.

Thank you for listening to me.

Dorothy Williams