

**Testimony of Jan Moss  
Family Caregiver  
Oklahoma City, Oklahoma  
Senate Finance Committee Hearing  
“Strategies to Improve Access to Medicaid Home and Community Based Services”  
April 7, 2004**

Mr. Chairman and Members of the Committee,

Thank you so much for the opportunity to testify today. I especially want to thank Sen. Grassley and Sen. Baucus for the invitation and Sen. Nickles for his long-serving leadership in representing the state of Oklahoma in the U.S. Senate.

My name is Jan Moss. I am a family caregiver and have been providing supervision and care to both my children (now adults) with developmental disabilities, and my husband’s parent(s) for a total exceeding 36 years. I am a widow now, and continue to have the same caregiving responsibilities that were shared when my husband was living.

I am here to support the President’s proposals for respite demonstration programs for both Medicaid enrolled adults and children as outlined in the proposed New Freedom Initiatives Medicaid Demonstrations Act. Given the serious funding shortfall for respite in most states, any new resources for respite would be a godsend. But I am also here to tell you about Oklahoma’s Lifespan Respite Care Program – the “Oklahoma Respite Resource Network” -- that has helped thousands of families not eligible for Medicaid, but in dire need of respite. I want to begin by thanking you and the entire Senate for its leadership in passing the Lifespan Respite Care Act which would help strengthen Oklahoma’s efforts and make Lifespan Respite systems available in more states.

When my children were young, I did not even know I needed respite. There were no respite projects or information explaining the need and support that respite provides. In recent years, I have made use of respite services and know the difference it has made in my life and in the well-being of my family. I am grateful and appreciative of this opportunity to share my personal experience to promote and explain the value and necessity of respite.

My husband and I divided our entire lives into “*pieces*” of care. Frequently, our time for each other was the missing “*piece*”. We reserved our paid leave for hospital “vacations.” We prioritized our employment according to who had the best benefits. The unusual care needs of our children affected every decision in our marriage and family life.

Except for the birth of my son, I went 18 years without taking a full day’s rest due to illness or injury. No wonder I have blocks of time for which I have little or no memory. Those years I call my “automized-suspension.” I was suspended in a fatigue fugue that allowed only for basic routine and automated behavior. I remember waking on our divan or in one of the kid’s rooms, but did not remember going to sleep there. I remember the year of Jennifer’s tendon transfer, the year of Jason’s heart surgery, eye surgery, hernia surgery, oral surgeries; the many heart caths, EEG’s EKG’s, ultrasounds, major uncontrolled seizures, or minor uncontrolled seizures, but I do not remember the birthday parties and anniversaries. Family pictures capture me at those events. I can prove I was there, but how sad, how tragic not to recall the benchmarks of my family.

Caregiver fatigue related directly to the spinal cord injury of my husband’s mother. She fell about 4 years into caring for my father-in-law who developed Parkinson’s, then Alzheimer’s disease. Ten years later, in addition to caring for my two adult children who still live at home, I now share a portion of my mother in-law’s care with my husband’s sisters.

The most difficult experience for me personally was the sudden death of my husband and care mate. On Fathers Day of 2000, he dropped dead from an undiagnosed heart problem. Now I see how important those missing pieces might have been to his health. Frightening me now is the loss of his income and my ability to maintain my health and responsibilities. It may seem heroic to you, but it is better to live for the sake of our family members who need care than to suffer and die for them. For who then will care, who then will supervise and manage the quality of care?

Respite, a brief separation from care giving, is natural. It is developmental in typical families. Constant care with no reprise for the spirit or rest for bodies is not heroic; it's dangerous and costly in fatigue related injuries and illnesses: falls, cuts, burns, not to mention prolonged stress that can lead to abuse and neglect, pharmacological mismanagement in missed dosages, over dosages, under dosages. I myself suffer from typical caregiver health issues, serious dental and joint disorders and the companion auto-immune issues associated with prolonged stress/tension.\_

When my daughter Jennifer turned 19, she became eligible for a "Home and Community Based Medicaid Waiver" and respite was one of the services offered. However, recent state budget cutbacks forced Oklahoma families to reduce or give up respite to lower the cost of their plans of care. If I want to continue to receive respite, I am going to have to give up other important services and supports and find a provider myself.

### ***Oklahoma's Lifespan Respite Program***

Thank goodness we have Oklahoma's Lifespan Respite Program, known as the Oklahoma Respite Resource Network, which could help me find new respite providers. The Network is a collaboration of 34 partners including three public agencies (DHS, Health Department and Mental Health), caregivers, advocacy agencies, private foundations and providers. This network has redirected almost \$1.8 million in public and private funds to respite care in Oklahoma and is able to serve families across age and disability categories.

The network was built on family support principles. Our system was built on the belief that caregivers are the experts and should be in control of the resources. Caregivers are given vouchers to purchase respite care from anyone they choose and negotiate the rate of pay. This can be another family member, friend, next door neighbor, day care center, home health agency, or a private provider. A survey completed in August of 2003 for the Oklahoma Respite Resource Network showed that 85% of the caregivers chose a respite provider from within their own natural support system.

If families need help in finding a respite provider, or finding out what programs they might be eligible for, they can turn to the Oklahoma Respite Resource Network. If a family desires training for a respite provider of their choosing, the state will provide that as well. The Oklahoma model has flexible funding, so the state can find the most cost effective way to deliver services, and allow caregivers control over resources.

This program currently serves approximately 2200 caregivers. For the past 3 ½ years the average cost for the respite vouchers has been between \$5.62 and \$5.87 per hour, compared with \$12.80 to \$26.50 per hour if the caregiver had chosen a provider from a private/public agency. This program has proven that caregivers are much more cost efficient with the resources.

Many policy makers think that when a caregiver or family needs support, that it will cost tens of thousands of dollars. We have shown that respite is a cost effective way to meet the needs of caregivers. In Oklahoma, caregivers are eligible for \$400 in vouchers every three months. In our survey, 47.7% of the caregivers said this amount was adequate to meet their needs; 52% said they could use more, but added that they needed just another \$100. This means that \$1600-\$2000 per year would meet the needs of 97.7% of the caregivers in Oklahoma.

We know respite allows caregivers to keep their loved ones at home longer, reduces stress, improves the stress levels in a home, reduces the risk of abuse and neglect and improves the quality of life of the caregiver and the care receiver. In the survey conducted by the Oklahoma Respite Resource Network, 88% of caregivers agreed that respite allowed their loved one to remain at home, 98% of caregivers stated that respite made them a better caregiver, 98% of caregivers said respite increased their ability to provide a less stressful environment, and 79.5% of caregivers said respite contributed to the stability of their marriage.

### ***Benefits of New Freedom Initiative Respite Demos***

On behalf of caregivers nationwide, I applaud the Administration's recognition that respite is central to the concept of home and community-based services. The New Freedom Initiatives Medicaid Demonstration Act respite demonstration proposal, which represents a small, but absolutely necessary infusion of funds for respite for the Medicaid population, may demonstrate that respite is a benefit worth providing under Medicaid. This is especially critical now when many existing state Medicaid waivers are eliminating or cutting back on the respite benefit because of serious state budgetary constraints.

With a focus on evaluating the effectiveness of respite in promoting home and community based services, the NFI provisions would also strengthen and add credence to respite findings from evaluations already underway by such national organizations as the ARCH National Respite Network and Resource Center that are demonstrating how effective respite is in keeping families together, strengthening marriages, and avoiding or delaying more costly out-of-home placements.

### ***Lifespan Respite Care Act (S. 538, HR 1083) Complements NFI Respite Demonstrations***

I also applaud the Senate for passing the Lifespan Respite Care Act (S. 538). This bill has been endorsed by the Lifespan Respite Task Force, a diverse coalition of over 180 national, state and local organizations. The NFI respite demonstration funds are critically needed and are fully complementary to respite systems that would be established by the Lifespan Respite Care Act. The NFI demos alone, however, will not address the respite care needs of millions of family caregivers who are not Medicaid eligible or currently not eligible for any government program. Under the proposed NFI respite demos, in addition to limiting eligibility to only those enrolled in Medicaid, states can limit respite to a specific geographic area of the state, to a limited number of individuals, or to specific disability or chronic condition.

Millions of these families and caregivers who would not be eligible under NFI sustain extraordinary expenses and sometimes even job loss due to the disability or chronic condition of their loved ones. As a result, many cannot afford respite. Even when family resources are available to pay for respite, finding quality respite that meets a family's needs and preferences, and is appropriate, safe, culturally acceptable, or geographically accessible may be impossible.

NFI respite demos are an important piece of the puzzle. If that piece is missing, the picture is not complete. But the Lifespan Respite Care legislation is the glue that holds the picture together.

The Lifespan Respite Care Act would allow states to provide the infrastructure for coordinating and maximizing use of all existing respite resources. Existing categorical federally or state funded respite programs often have limited reach because of restrictive eligibility criteria, limited funding, and long waiting lists. Other federal or state programs may have the potential to fund respite, but often don't because of limited resources and

competing demands. As a result, families often do not know where to turn to find or pay for respite resources.

Under the lifespan approach, states can identify and coordinate existing respite resources, pool and share providers, funds, training resources and administrative capacities, and identify and fill gaps in services. The Lifespan Respite Care Act provides a way to improve efficiency, save money, and make quality respite available and more accessible to families and caregivers, regardless of their Medicaid status, disability, or age.

Lifespan respite programs also exist in Oregon, Nebraska and Wisconsin. With flexible funding and requirements, each program has been adapted to meet their individual state needs, but the defining characteristic of each is the statewide, coordinated approach to ensure respite services for those in need. Many of the lifespan respite programs have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, state and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities and volunteers.

These networks are the central point of contact for families and caregivers seeking respite and related support regardless of age, income, race, ethnicity, special need or situation. Respite stipends may be limited by income eligibility, but are generally more generous than existing programs. Providing a single point of contact for families to access respite information and services is crucial to assisting families in helping themselves.

Services typically offered by Lifespan Respite Programs are providing public awareness information to the community and building diverse respite partnerships, recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services.

### ***State Medicaid Programs Work Cooperatively with State Lifespan Respite Programs***

Precedent has already been set by these State Lifespan Respite Programs for cooperative working and funding arrangements with State Medicaid agencies. In Nebraska, the regional Lifespan Respite Network Coordinators recruit providers for Medicaid, as well as for the Lifespan Respite Program. The Coordinators meet with staff from HHS, DD, Early Intervention Program, etc. on a monthly basis in order to determine need. Respite providers are recruited and trained to fill the gaps, and provider lists are shared.

Oregon was the recent recipient of a CMS demonstration grant for respite care for children with disabilities this fiscal year. The state will be doing a feasibility study to look at how Oregon's Lifespan Respite system could be the structure for implementation of that effort. Secondly, local community Lifespan respite registries share providers. Local coordinators also share training resources and criminal background checks. The Medicaid Home and Community Based Waivers that pay for respite in the state have Medicaid case managers coordinate with local Lifespan Respite Network coordinators.

I urge you to support the President's proposed NFI respite demos, which would provide benefits to some very needy families and caregivers, and infuse funds for critically needed respite services, training and evaluation. At the same time, it is my belief that these benefits would not be fully realized without enactment of the Lifespan Respite Care Act as well. I urge you to work with the House colleagues to move the Act forward. Thank you for this opportunity.