

**Written Testimony**  
**of**  
**Suzanne Mintz, President/Co-founder**  
**National Family Caregivers Association**  
**Presented to**  
**U.S. Senate Special Committee on Aging**  
**As Part of the Hearing on Family Caregiving in the**  
**Older Americans Act: Caring for the Caregiver, May 17, 2001**

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Mr. Chairman, members of the Committee thank you for this opportunity. My name is Suzanne Mintz, and I am the President and Co-founder of the National Family Caregivers Association (NFCA). NFCA exists to educate, support and empower family caregivers and speak out publicly for meeting caregivers' needs. We reach across the boundaries of differing diagnoses, different relationships and different life stages to address the common concerns of all family caregivers.

Our members care for spouses, children, aging parents, siblings, friends and others. Half are caring for seniors, 66 or older and most are "heavy duty" caregivers, meaning they are providing hands-on care on a daily basis, helping loved ones, dress, bath, toilet etc. For three fifths of these caregivers, caregiving is the equivalent of more than a full-time job.

I have been asked to talk to you about the needs of family caregivers, especially the unmet ones and how the National Family Caregivers Support Program might meet them. If you have never been a family caregiver yourself, it is truly difficult, if not impossible, to completely appreciate the impact that caregiving can have. Numerous studies have shown that heavy duty caregivers, such as the ones we talk to everyday at NFCA, experience high levels of anxiety and frustration; feel isolated from other people, even other family members; don't know where to turn for help; want and need some time for themselves; and are prone to depression at higher rates than the rest of the population. This catalogue of circumstances and difficult emotions underlies the unmet needs of family caregivers but doesn't speak to them directly. This is what caregivers say:

*"I am on call 24 hours a day. Last night I was up for two hours because he (my husband) wet the bed, and I had to get up to change him and the bed.... I am just stressed out. I have come to a point where I am just really worried all the time... Charles has dementia, too. It makes it very hard for me because I'm lonesome.... We're getting along on what we have, but if I have to buy any more medicine, it is going to be tough. Caregiving is an emotional, financial and physical drain that takes up a lot of energy. If I could be selfish, I would ask to have a wee bit of time just to dress up. I look grungy all the time and seldom get to shower because there's nobody here. I can't leave him alone too long."*

Frances McArty, 80 years old, Champaign, IL

*"My sister has cancer, is diabetic and has a colostomy, and I have to do the care for all of that.... My sister doesn't have much education, and I have to take care of practically everything for her. This past week I had a problem. I didn't want to leave my sister by herself, and I called someone but most people are afraid to stay with anyone who is sick because they're afraid something is going to happen while you're gone. But I had to get an eye exam; this place was 35 miles away. It's not like I was gone overnight or anything, but people just don't know what to do.... I do very well if I have somebody that I know I can depend on, but if I can't get a hold of someone and I don't know what to do, it excites me, it rattles me because I'm afraid I'll make a mistake. It could mean somebody's life, and you think about that a lot.*

James Lassiter, 62 years old, Lepanto, AR

These two anecdotes speak to the very real and unmet needs of family caregivers. They speak to the need for:

- Assessment of a caregiver's individual needs and circumstances, including emotional resources, physical capabilities and practical knowledge,
- Training to help caregivers learn the skills that apply to their particular caregiving circumstances and training to help them learn how to manage, plan and cope with their caregiving responsibilities,
- Respect for the work they do and peer support to validate their feelings and experiences and provide them with knowledge and tips from the trenches,
- One-on-one advice and assistance from those who know the "system", understand the issues and can help caregivers access needed resources,
- One-on-one assistance to help caregivers think through and manage the decisions they need to make, so that in the long run they can be a more effective caregiver and a healthier human being,
- Financial support to offset the expenses of caregiving,
- and last but certainly not least, high quality respite services that meet the individual needs and circumstances of a caregiver's life.

The National Family Caregiver Support Program can begin to address many of these needs, but certainly not all of them. The Program is a start and provides the first national mandate for serving a portion of our nation's family caregivers, and the Committee should be very proud of its role in making it a reality. Meeting the needs of family caregivers is a complex process, and I think much can be learned by looking at programs that have already been established and are successful.

In 1999 the Family Caregiver Alliance in San Francisco, published a report entitled *Survey of Fifteen States' Caregiver Support Programs*. Thirty-three state-funded programs that serve the needs of family caregivers were reviewed. Five stood out as "best practice" models:

- California's Caregiver Resource Centers,
- New Jersey's Statewide Respite Program,
- New York's Consumer and Family Support Services Program,
- Oregon's Lifespan Respite Care Program, and
- Pennsylvania's Family Care Support Program.

Although there are obviously differences between the programs, there are also common themes among them including:

- Provision of respite care,
- A focus on consumer-directed care,
- Flexibility of program services, and
- Broad income eligibility.

I would recommend this report to the Committee for reference. Much can be learned from the experience of others. And I can tell you, as a family caregiver myself these common themes resonate with me.

If I can paraphrase the comments of state program personnel from the report, and add my voice to the chorus, we want to see:

- Programs that are designed with input from the people who need them so they can really meet the needs of their community,
- Programs that are flexible and are designed to meet a caregiver's needs in creative ways, rather than being so tightly prescribed that they only allow for a predetermined solution and,
- Programs that provide caregivers with more access to respite that allows family and friends to provide care when appropriate. At times, that might be the only way caregivers are willing to take a break and the only way care recipients are willing to accept care from someone other than the primary caregiver.

The National Family Caregivers Support Program is the first federal program to specifically reach out to family caregivers. Even in its first year of implementation, it needs to stand as a beacon so that other programs will follow. The National Family Caregivers Support Program should focus on providing real services that make a difference in people's lives, meaningful services that are available as soon as possible so that their impact can be felt. Keeping sight of the goal, actually helping more family caregivers as soon as possible, working creatively with

existing service providers to maximize available dollars and doing so all within a targeted time frame can help insure its early success.

Before I close I would like to draw the Committee's attention to a piece of legislation that has not yet been passed that would provide a valuable corollary to the National Family Caregivers Support Program and that is S627, The Long Term Care and Retirement Security Act of 2001. This bill would help all of us prepare for the cost of long term care by providing a tax deduction for the purchase of long term care insurance, and right now it would help existing caregiving families by providing them with a \$3,000 tax credit to help assuage the out-of-pocket medical costs of caregiving, costs that are considerable and have been measured at 11.2% of income for families in which one member has a disability. I encourage the Committee members to co-sponsor it and want to thank Senators Breaux, Collins, and Lincoln for already doing so.

Thank you for your time and attention.