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Senate Committee on Health, Education, Labor and Pensions

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Mr. Chairman and Members of the Subcommittee:

On behalf of the National Respite Coalition, I am pleased to submit this testimony in support of the "Lifespan Respite Care Act of 2002," to be introduced by Senators Clinton, Mikulski and Snowe. Seventy-five national, state and local organizations have already endorsed this bill, which grew out of the efforts of the National Respite Coalition's Lifespan Respite Task Force, a coalition of national organizations and state respite coalitions.

The National Respite Coalition is the policy division of the ARCH National Respite Network and Resource Center. The ARCH Network is a membership organization of respite providers, state respite and crisis care coalitions, and the families and caregivers who rely on planned and crisis respite services. The ARCH National Resource Center on Respite and Crisis Care is a federally funded resource center providing: training and technical assistance; product development including a start-up manual, National Respite Guidelines, fact sheets, training manuals and evaluation reports; a National Respite Locator Service; networking opportunities; and evaluation and research.

Over the last several years, the National Respite Coalition, following the leads of its state respite coalitions, helped spearhead a national movement to address the respite and caregiving needs of all families across generations, across disability groups, and regardless of family situation or income level. Partnering with over 25 other diverse national and state organizations in a working group called the Lifespan Respite Task Force, the NRC helped highlight the need for high quality, accessible and affordable respite services across the lifespan.

We are extremely grateful for the strong national leadership Senator Clinton, Senator Mikulski and others on the Subcommittee have already shown on family caregiving issues. We strongly support the implementation of the National Family Caregiver Support Program, which is helping expand and support respite and support services primarily for caregivers of the elderly. It is an important first step and we commend you for all your efforts in this area.

What is Respite?

Respite care provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs, or who may be at risk of abuse or neglect.

Respite is first and foremost a preventive strategy that strengthens families, protects the health and well-being of the family, and allows them to continue providing loving care at home. Respite is also an important component of a continuum of comprehensive family support and long-term care services that are available to caregivers not only on a planned basis, but also in the event of a crisis situation, such as sudden job loss or homelessness.

Who Needs Respite?

The sheer numbers of women in this country, many of whom place their own emotional and physical well-being in jeopardy by providing continuous care with no break and limited support, are enough to raise and justify concern. Current estimates suggest that there are between 24 million and 28 million family caregivers in America. Nearly 45% are caregivers of nonelderly adults and children. The remaining are caring for the elderly. By 2020, the number of adults requiring assistance with daily living will increase to almost 40 million, requiring a tremendous spurt in the numbers of family caregivers.

This is especially relevant to women's health, since 75% of the caregivers nationwide are women.

Moreover, new family arrangements, such as growing numbers of grandparents caring for grandchildren, also suggest a need for new and effective support services. Currently, there are more than 2.5 million grandparent-headed households raising 3.9 million children in the U.S. The number of these families without either parent present increased 53% between 1990 and 1998 and now over 1.3 million children are being raised solely by their grandparents. Despite these statistics, most states and counties do not fund respite for these caregivers.

Caregivers, who are raising young children while caring for an aging parent or relative, bring their own set of stressors and add to the growing need. It is estimated that between 20 and 40 percent of caregivers have children under the age of 18 to care for in addition to a parent or other relative with a disability.

In addition, families of children with disabilities or chronic illness have unique and ongoing needs that present special demands and can increase family stress. Over six million children are eligible for or receive special education and related services under the Individuals with Disabilities Education Act (IDEA). Many have estimated the number of children with serious disabilities and chronic illness to be even higher.

Unmet Need and the Dire Consequences

Survey after survey of family caregivers has shown respite to be the most often requested family support service, and yet it remains in critically short supply.

Twenty of 35 state-sponsored respite programs surveyed in 1991 reported that they were unable to meet the demand for respite services. In the last ten years, we expect that not too much has changed. The thirty state coalitions and other National Respite Network members confirm that long waiting lists or turning away of clients because of lack of resources is still the norm.

According to the ARCH National Resource Center on Respite and Crisis Care, during an average week, nearly 1,500 families representing 3,425 children are turned away from respite and crisis care programs because resources to meet the need are absent. In the absence of any hard data, but countless compelling family stories, we know that respite for adults with disabilities and chronic illness is also in critically short supply.

The lack of support is taking its toll on caregivers. While a large proportion of caregivers, most of whom are women, report finding an inner strength they didn't know they had, a National Family Caregivers Association survey found that significant numbers report serious physical or mental health problems, including headaches, stomach disorders, back pain, sleepless nights and depression. Mortality risks are even higher for caregivers than for noncaregivers. A 1999 study reported in the Journal of the American Medical Association found that participants who were providing care for an elderly individual with a disability and experience caregiver strain had mortality risks that were 63% higher than noncaregivng controls.

Grandparent caregivers report face enormous financial stress, as well as the poor health status. In 1997, grandparent caregivers were 60% more likely to live in poverty than grandparents not raising grandchildren. In addition, one-third of grandparents in all grandparent-maintained families self-report their general state of health as fair or poor.

In fact, we cannot afford to lose any family caregivers to stress or illness. According to the National Long-Term Care Survey, if the work of family caregivers had to be replaced by paid home care staff, the cost to our nation would be $45 to $75 billion per year. Other studies have suggested that caregivers now provide nearly $200 billion per year in unpaid care, saving the government billions of dollars in paid institutional long-term care costs.

Those who are being cared for are at high enough risk already without having their caregivers face uncertain illness or even death. And for many, the families suffer emotionally as well as economically. Families of children with disabilities face a significantly higher divorce rate than families of children without disabilities. Lack of respite care has even been found to interfere with parents of children with disabilities accepting job opportunities.

Even tragedy can result. The number of children and the elderly who are annually reported as abused or neglected, whose families could benefit from respite services to prevent the abuse from happening in the first place, is unacceptable. Each year, CPS agencies investigate an estimated 2 million reports alleging the maltreatment of almost 3 million children. In addition, it is estimated that 2 to 4 million women are victims of domestic violence and between 3.3 and 10 million children are exposed to domestic violence, each year. Without adequate family support, children with disabilities face an even higher risk of abuse and neglect (nearly 4 times higher).

The abuse rate of the elderly is also unacceptably high. Experts estimate that as many as

32 out of 1,000 elderly people are victims of elder abuse. A 1996 national incidence study found that 450,000 persons ages 60 and over in domestic settings experienced abuse or neglect in a one- year period. It is estimated that over five times as many new incidents of abuse and neglect were unreported than those that were reported to and substantiated by Adult Protective Services agencies that year. In 90% of cases, the perpetrator is a family member.

Respite Works and Saves Money

While much more rigorous evaluation needs to be done, respite has been shown to improve family functioning, improve satisfaction with life, enhance the capacity to cope with stress, and improve attitudes toward the family member with a disability.

Most compelling are recent preliminary data from Phase One of the ARCH National Resource Center Outcome Evaluation project. Twenty-nine respite and crisis care programs serving families across the lifespan in the Midwest, South, East coast, West Coast, Southwest, Alaska and Hawaii volunteered to participate. Seventeen programs remained engaged in the project and participated in the field-testing of the instruments. Based on their knowledge of the families' activities and past history, project managers reported that in some instances caregivers were likely under reporting on issues such as maltreatment, out of home placement and marital status. Even with some qualifications, the preliminary data are very encouraging.

Although parents were reluctant to admit that their child would have been at risk for maltreatment had crisis care not been available, caregivers reported that the crisis care they received helped protect their child from danger. Fifteen (15%) percent of the caregivers of children using crisis respite reported that it was "somewhat likely" to "highly likely" that their child might have been mistreated or neglected if crisis care had not been available, and an additional 15% responded "not sure." Yet, 81% reported that the crisis care they received helped protect their child from danger. In terms of marital stability, nearly half (47%) of the caregivers surveyed in respite programs serving all age groups said that they would be somewhat, quite or highly likely to experience separation or divorce without respite services.

Respite helps families avoid more costly out-of-home placements as well. Hospitalizations, institutionalization, nursing home and foster care placements have been shown to actually decline when respite or crisis care is the intervention. The Nebraska lifespan respite program conducted a statewide survey of a broad array of caregivers who had been receiving respite services, and found that one out of four families caring for a child under 21 and one out of two families caring for a family member over 21 reported that they were less likely to place their family member in out-of-home care once respite services were available.

Most importantly, the health and well-being of women and others who provide the care has been shown to improve. Sixty-four percent of caregivers of the elderly receiving 4 hours of respite per week after one year reported improved physical health, 78% improved their emotional health, and 50% cited improvement in the care recipient as well. Forty percent said they were less likely to institutionalize the care recipient because of respite. Caregivers of relatives with dementia who use adult day care experience lower levels of caregiving related stress and better psychological well-being than a control group not using this service. These differences are found in both short-term (3 months) and long-term (12 months) users. In addition, the Nebraska Lifespan Respite program found that 79%-80% of the respondents reported decreased stress and 58%-65% reported decreased isolation as a result of respite services received through the program.

State Family Caregiver Support Programs

Over the last decade, states have begun to respond to this growing need and have implemented caregiver support programs in various forms.

In a Family Caregiver Alliance (FCA) survey of 33 caregiver support programs in 15 states, it was found that eligibility criteria for programs vary widely by diagnostic /functional level, age and income. Over two thirds of these programs provide five or more caregiver services, most typically respite care. For respite assistance in particular, service definition, eligibility, mode of delivery and funding vary widely across programs and within states. Key informants report that while respite care is among the most beneficial aspects of their programs, recruiting respite workers/raising worker wages is also among the biggest challenges these state programs face.

Oregon=s Lifespan Respite Care Program (see below) was identified as one of the five best practice models among the 33 programs surveyed by FCA and at the time of the survey was the only statewide program with no eligibility criteria based on disability, income, or age. Wisconsin, Nebraska and Oklahoma now all have statewide lifespan respite programs (see below). The private sector, including Easter Seals, United Cerebral Palsy, and the Alzheimer's Association are also involved in providing and supporting respite services. An intergenerational program, Family Friends, partners active senior volunteers with families of children with disabilities to provide respite, friendship and nurturing.

Fragmentation and Unmet Need

Despite the model efforts discussed so far, and the success respite brings in terms of family stability and cost-savings, the need for state and national respite care infrastructure is compelling. Most of the problem can be attributed to insufficient resources directed specifically at start-up, development, implementation and maintenance of quality respite care choices.

The current supply of individuals available to provide respite care is woefully inadequate in many communities, especially respite care for individuals with certain disabilities such as mental illness or severe medical conditions, especially those over age 18, or in some rural and urban centers where these resources may be scarce.

However, an equally difficult problem is the identification and coordination of existing resources that would aid caregivers and help state agencies improve access to respite programs.

Implementation of the National Family Caregiver Support Program is helping develop statewide infrastructures and single points of entry through Area Agencies on Aging to help primarily caregivers of the elderly more easily find the respite and support they need. Existing statewide respite and caregiver support programs are also a small step in the right direction, providing access to some respite services statewide for some part of the needy population.

While these efforts provide a critically important foundation on which to build, they currently do not do enough to reduce the fragmentation, the inaccessibility, and the confusion that exists around multiple eligibility criteria, numerous funding streams, and qualified provider shortages.

Numerous funding sources with different eligibility criteria are partly to blame.

A myriad of other federal programs, including Medicaid, Medicaid Waiver programs, Title XX Social Services Block Grant, the Community-Based Family Resource and Support Program, the Child Care and Development Block Grant, and the Developmental Disabilities Program, among others, have been identified which have the potential to fund or support respite care for caregivers, but only for caregivers of individuals with specific disabilities, specific ages, or for one narrow purpose.

These limitations are confusing not only to families, but to the states that rely on them. In addition, while many of these programs have the potential to fund respite and crisis care, they are not mandated to do so. Competing demands for these funds or lack of information on the part of consumers as well as state agency heads often results in no or limited federal funds from these various programs being used to support respite care.

Currently, there is no single, coordinated, family/caregiver friendly federal program to support the development or implementation of respite care infrastructures that would serve all families regardless of the age of the caregivers or the ages or disabilities of the care recipients.. Families are now forced to search for services, funding, and support, where they may or may not exist, often in a complicated bureaucratic maze.

Lifespan Respite

As of April 2002, three states had passed Lifespan Respite Acts (Oregon, Nebraska, Wisconsin), which establish state and local infrastructures for developing, providing, coordinating and improving access for respite to residents of the state. Oklahoma has implemented a statewide Lifespan Respite Program without legislation. Maryland has enacted legislation that establishes a State Coordinating Council for Family Caregiver Support. Part of Maryland's charge is to review successful lifespan respite care programs in other states, develop a model family caregiver support program that incorporates best practices from existing programs in the state and in other states; and coordinate activities of existing and proposed family caregiver support services among the state and local public agencies. Several other state coalitions or governments (Alabama, Connecticut, Florida, and Montana, among others) are actively considering or piloting similar lifespan respite programs or legislation.

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 all who need it. 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. Providing a single point of contact for families to access respite 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 of paid and volunteer respite providers, connecting families with respite payment resources, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services, and connecting families with respite providers.

Oregon was the first state to implement a Lifespan Respite Program in 1997. The Director of the Oregon Department of Human Services (DHS) is charged by state law to develop and encourage statewide coordination of respite care services. The Department works with community-based nonprofits, businesses, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet those needs. Oregon=s Lifespan Respite Program is housed in the DHS Community Partnership Team and is responsible for implementing the Oregon Lifespan Respite Care Act, administrative rules, contracts, funding and program evaluation. The Program offers technical assistance with program specific issues, works directly with Lifespan networks and promotes the state respite agenda. Currently there are 29 Lifespan Respite Care Networks representing 34 Oregon counties. All of Oregon=s counties are expected to be served by 2003.

Nebraska builds on the Oregon model and is currently administered by the state=s Department of Health and Human Services, which established the Nebraska Lifespan Respite Services Program. With the goal of helping create a permanent structure for a statewide system for respite, NLSRP designated and funded six community lifespan programs this past year. The organizations which received the contracts with Health and Human Services will be expected to accomplish the following five outcomes within the initial two-year contact period: 1) A knowledge of all existing respite resources within the designated HHS service area and the need for additional resources by lifespan populations; 2) An increased public awareness of lifespan respite among families, providers, local agencies, Medicaid staff and the private sector within the designated HHS Service Area; 3) An increase in the access to lifespan respite services; 4) Knowledge of and collaboration with existing agencies on best practices for a comprehensive training package for providers and family members; and 5) Documentation of an increase in the awareness of respite, an increase in Medicaid respite providers, an increase in the representation of all cultural groups, better access to respite services and other baseline data established by HHS to be used for program evaluation.

In Wisconsin, the legislation authorizing the Wisconsin Lifespan Program requires that coordinated, noncategorical respite services be available locally to provide reliable respite services when needed by families and caregivers regardless age, disability or geographic location in Wisconsin. In collaboration with the Department of Health and Family Services, the Respite Care Association of Wisconsin (RCAW), the state administering body of the Wisconsin Lifespan Respite Program provides administrative oversight to the lifespan grantees, offers technical assistance around program and workforce specific issues, and promotes the state respite agenda. In 2000, RCAW awarded grants to establish five regional lifespan programs, one in each of the five Department of Health and Family Services regions across the state. By 2005, it is expected that 25 lifespan projects will be created in the state.

The Oklahoma Respite Resource Network (ORRN) is a statewide partnership of public and private agencies whose goal is to support families and caregivers by increasing the availability of respite care. State agencies, including developmental disabilities, mental health, aging, maternal and child health and others, have come together voluntarily with private agencies to pool resources for respite and dispense them though a voucher program managed by a single state program. Families applying to the state for a respite voucher (families are entitled to $400 in vouchers for 3 months) are considered the employer of the respite care provider and are encouraged to consider as potential respite providers family, friends or co workers, civic organizations, local churches, child care centers, or other appropriate public or private agencies. The Oklahoma Respite Resource Network also relies on an already existing statewide resource and referral system (OASIS) to link families to the program.

Time has Come for a National Lifespan Respite Policy

Building on the fervent activity at the state level, and the converging demographic and social trends that face all families and caregivers across the nation, the National Respite Coalition has found unprecedented support among a diverse group of national organizations for pursuing a national lifespan respite policy.

The NRC held a National Summit on Lifespan Respite in May 2000. Over thirty national organizations attended and a core group has been meeting as the Lifespan Respite Task Force regularly since then. Our first major activity was the development of a common respite definition, a vision statement and a set of principles of quality respite care. Twenty-seven national organizations and 17 statewide organizations endorsed the vision statement and principles.

The Task Force's efforts were bolstered by the National Conference of State Legislatures response to assist states in planning around the Olmstead decision, a Supreme Court decision which requires every effort by the federal government, states and local agencies to serve individuals with disabilities in the community, rather than in institutional settings. NCSL published an issue brief on implementing long-term care in community-based settings which highlighted lifespan respite as one of three best practices models for state action. The Nebraska program was highlighted as an example.

We are also heartened by the Administration's Department of Health and Human Service's focus on respite care for supporting family caregivers during implementation of the Olmstead decision in its recently released report "Delivering on the Promise." Recommendations included two new demonstrations for respite for the adults with disabilities and for children with severe disabilities to be administered through the Center on Medicaid and Medicare. While we applaud the Department's recognition that respite is needed by all age groups, and their efforts to increase the availability of respite care, it is another piecemeal approach that does not go as far as the Lifespan Respite Care Act of 2002 to ensure that duplication and fragmentation of services are eliminated, and that barriers to quality respite care across the lifespan will be reduced for caregivers struggling to keep their loved ones at home.

Lifespan Respite Care Act of 2002

We know how families are changing and how rapidly a large proportion of the population is aging. The demographics make that clear. Fortunately we know what to do to support families. We commend the cosponsors of the "Lifespan Respite Care Act of 2002" for following the states= leads to make sure that every state has the resources and encouragement to institute their own lifespan respite program. This bill would authorize funds for:

- development of lifespan respite programs at the state and local levels;
- evaluation of such programs;
- planned or emergency respite care services;
- training and recruitment of respite care workers and volunteers; and
- caregiver training to help make informed decisions about respite care services.

Lifespan respite programs are defined in the bill "as coordinated systems of accessible, community-based respite care services for all caregivers of individuals regardless of the individual's age, race, ethnicity or special need."

Caregivers who are family members (including grandparents caring for grandchildren), foster parents, or other adults providing ongoing unpaid care for an individual with a special need. Special need is defined broadly as: Alzheimer's disease and related disorders; developmental disabilities; mental retardation; physical disabilities; chronic illness; behavioral, mental and emotional conditions; situations in which there exists a high risk of abuse or neglect or of being placed in the foster care system; in which a child's parent is unavailable due to parent's death, incapacitation, or incarceration of a parent; or any other conditions established by regulation.

Funds would be provided on a competitive grant basis to state agencies, other public or private nonprofit entities capable of operating on a statewide basis, a political subdivision of a state that has a population greater than 3 million, or any already recognized State respite coordinating body. Priority would be given to applicants that show the greatest likelihood of implementing or enhancing lifespan respite care statewide.

Coordination is also required at the federal level between the administering agency, the Maternal and Child Health Bureau of the Health Resources and Services Administration and the following federal agencies: National Family Caregiver Support Program of the Administration on Aging, the Administration for Children, Youth and Families, the Administration on Developmental Disabilities, and the Substance Abuse and Mental Health Services Administration.

Funding for the bill is authorized at $90.5 million in FY03 and rises to $200 million in FY07. The bill would also establish authority for a critically needed National Resource Center on Lifespan Respite Care that would assist states and local programs in developing and enhancing new respite services; maintain a national database; provide training and technical assistance, and information to the public on lifespan respite care.

This legislation is timely and will help create a family caregiving policy in our country, not just a band-aid solution. Families are under greater stress than ever before and the numbers of women who will assume caregiving roles without adequate support in the coming decades are rising at an alarming rate. Respite works, respite saves money, and it=s what families and caregivers say they want and need.

Thank you for the opportunity to provide written testimony to the Committee in these very important deliberations. The National Respite Coalition stands ready to provide assistance in rapid enactment of this critically important legislation.