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WHO CARES FOR THE CAREGIVERS? THE ROLE OF HEALTH INSURANCE IN PROMOTING QUALITY CARE FOR SENIORS, CHILDREN AND INDIVIDUALS WITH DISABILITIES

HEARING

BEFORE THE

OVERSIGHT OF GOVERNMENT MANAGEMENT,
RESTRUCTURING, AND THE DISTRICT OF COLUMBIA
SUBCOMMITTEE

OF THE

COMMITTEE ON
GOVERNMENTAL AFFAIRS
UNITED STATES SENATE

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TUESDAY, JULY 24, 2001

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WHO CARES FOR THE CAREGIVERS?: THE ROLE OF HEALTH INSURANCE IN PROMOTING QUALITY CARE FOR SENIORS, CHILDREN AND INDIVIDUALS WITH DISABILITIES

TUESDAY, JULY 24, 2001

U.S. SENATE,
OVERSIGHT OF GOVERNMENT MANAGEMENT, RESTRUCTURING,
AND THE DISTRICT OF COLUMBIA SUBCOMMITTEE,
OF THE COMMITTEE ON GOVERNMENTAL AFFAIRS,
Washington, DC.

The Subcommittee met, pursuant to notice, at 2:30 p.m., in room SD–342, Dirksen Senate Office Building, Hon. Richard Durbin, Chairman of the Subcommittee, presiding.

Present: Senator Durbin.

OPENING STATEMENT OF SENATOR DURBIN

Senator DURBIN. Good afternoon. The Subcommittee on Oversight of Government Management, Restructuring, and the District of Columbia, of the Senate Governmental Affairs Committee is now convened. The hearing will come to order. Thank you all for being here. Today, the Committee is going to consider the role of health insurance in promoting quality care for seniors, children and individuals with disabilities.

I might say at the outset for those who will be here for the duration of the hearing, that at 3:40 p.m., there will be a moment of silence on the floor of the Senate for the two officers who were killed in 1998, in protection of the visitors and staff and members of the United States Capitol. On July 24, 1998, at 3:40 p.m., Office Jacob Chestnut and Detective John Gibson of the U.S. Capitol Police were killed in the line of duty defending this Capitol against an intruder armed with a gun. So, at 3:40 p.m. today, we will recognize the anniversary of this tragedy by observing a minute of silence in their memory. We hope that you will join us in this symbol of respect for our fallen comrades.

We will recess the Committee at about 3:30 or 3:35, and then return immediately after that moment of silence on the floor of the Senate. I wanted to say that in advance. Again, thank you all for being here. Today, over 2 million Americans provide professional care to our most precious resources: Our children, our parents, and our brothers and sisters with disabilities. Many of these important caregivers are paid very little and they do not have health insurance to cover their own health care needs or the health care needs of their family. This low pay and lack of benefits lead to a very high staff turnover in these jobs.

For instance, in child care facilities, there is a turnover rate of more than 33 percent, and for nurses aides working in nursing homes, turnover can be as high as 94 percent each year. Clearly, this constant change of staff can affect the quality of care being received. If the staff is constantly turning over, it can be pretty frustrating for an employer to train new staff, only to see them leave in just a few months. It can also be very expensive. But for those being cared for, a lack of adequate training of their caregiver can really affect the quality of care that they received. Studies have shown that children attending lower-quality child care facilities and child care facilities with high staff turnover are less competent in language and social development. Likewise, the quality of care for seniors and individuals with disabilities is diminished when high turnover acts as a disincentive to the provision of appropriate training.

Our hearing today will focus on the need for and availability of health insurance for hard-working caregivers. Job benefits are one tool that can help with job retention. Of course, there are other ways to also help improve care. In my own home State of Illinois, a recent survey showed that 57.7 percent of home care workers under the age of 65 had no health insurance. Let me repeat that: 57.7 percent of home care workers under the age of 65, without health insurance. This compared to 14.7 percent of Illinoisans in general who had no health insurance. By my calculation, that means that the rate of uninsured is four times higher for those who work as home care workers.

The report also found that in the past year, 41.3 percent of the Illinois home care workers had to choose between buying food and paying their medical bills. The State of Rhode Island, represented today by Jane Hayward, has already recognized the importance of health insurance to caregivers. They pioneered the concept of providing health insurance to certain caregivers. We will be hearing about that today. We will be hearing about their success with child care workers. Rhode Island was so convinced of the importance of improving the quality of care through providing health insurance that the State funds the program entirely with its own money.

With the full implementation of welfare reform, it is particularly important that high-quality child care be available for the children of those who are returning to the workforce. We will have done the country a clear disservice if children suffer from our efforts to promote work. The first few years of a child's life are critical. More and more studies are demonstrating how early childhood development is critical to later success. There can be many benefits from providing health insurance to caregivers. Not only can it help with retention, and therefore improve the quality of care, but it can also help caregivers themselves stay in better health. Many caregiving jobs are tough jobs. They are stressful. The job can be both physically and emotionally demanding, and if a caregiver's own health is compromised because he or she does not have health insurance, this can make the job even more difficult.

We will be hearing today from individuals who themselves work as caregivers. In some cases, they have health insurance, but it may not extend to their family members. I know they will be able to tell us about how important health insurance is to them. We will also be hearing from the National Family Caregivers Alliance. They represent family members who are themselves caregivers. This is an important category. We talk about caregiving as an occupation with a paycheck. There are many caregivers who stay at home with members of their families, who do not receive a paycheck, but give as much care, if not more, than anyone working a 9 to 5 job.

As we all know, many family members make incredible sacrifices to look after their loved ones. The California Caregiver Resource Center estimates that family caregivers who attend to those with Alzheimer's, stroke, Parkinson's, traumatic brain injury, or other adult-outset brain-impairing diseases and disorders provide an average of 73 hours of care each week, more than 10 hours a day; 16 percent of family caregivers report their health has worsened since becoming a caregiver, and clearly access to health care service is important to them. These family members perform a wonderful service, allowing their relatives to remain in the community.

Some family members are forced to quit their own job so they can take care of a relative. This sometimes means that they lose their own health insurance. This can happen at any age. Over 40 million Americans are uninsured today. We live in the wealthiest country in the world and still so many lack access to the most fundamental benefit, health insurance. Personally, I think it is time we move forward to eliminate this blemished record. We have made progress in the last few years with enactment of the State Children's Health Insurance Program. Hopefully, we will extend it this year to cover the parents of those kids. A good next step would be to provide States with resources in the same manner that we did with the Children's Health Insurance Program and allow the States themselves to design programs to extend coverage to caregivers.

The Children's Health Insurance Program was voluntary; no State was obligated to participate, but every State has chosen to do so. States now have experience with the program. Many have learned from the experience. It is really an ideal model to build on. Such an approach would avoid duplication and can be administratively very cost-effective. We all talk about how much we value caregivers. I think it is time we step up to the plate and show how much we care by ensuring that all caregivers in America have health insurance.

It always struck me as curious, as I visited daycare facilities, nursing homes, and spoke with the disabled, that we entrust our most valuable assets on Earth to these people, and yet we know that it is a very tough job; it is very stressful; it pays usually little more than a minimum wage and has no health care benefits. It is said that if you want to know how a community values education, drive by the school and take a look. If it is run and beat up, there is a possibility that there is not the keen interest in education that they might profess when they speak to others from other towns. I think the same is true when you look at people who are caregivers. How much do we love our children and grandchildren? How much do we love these parents and aunts and uncles, who need help in a nursing home or a convalescent center? How much do we care for those disabled among us who need a personal attendant, perhaps, just to make their lives really work each day, so that they can be part of our community and make a real contribution to America?

The real test is the pocketbook test. How much money are we putting on the table here? What I am suggesting is to follow the lead in Rhode Island, which has come up with, I think, an innovative program that can give us some guidance as to how much this program can mean if we do it on a Federal basis. I would like now to welcome and introduce today's panel of witnesses: Jane Hayward, Deputy Director of Rhode Island's Department of Health and Human Services. You have sent us some excellent senators and we are happy that you came down yourself to join us today.

Ms. HAYWARD. Thank you very much.

Senator DURBIN. The State of Rhode Island has pioneered the idea of caregiver health insurance and used their own State funds to enact the RIte Care program, providing health insurance to child care workers through Medicaid. Suzanne Mintz is the President and Co-founder of the National Family Caregivers Alliance. She has over 20 years of experience as a family caregiver and as a businesswoman. She co-founded this organization to represent families that care for their loved ones.

James Stearns, former President of United Cerebral Palsy—this nationwide organization represents patients with cerebral palsy and other disabilities who are often in need of caregiving.

Yolanda Sims from Springfield, Illinois is an aide at the Hope School for the Developmentally Disabled. She will share examples from her own experience of the importance of health insurance to a caregiver, and I will confess at the outset, as I told her earlier, I know about Hope School, at least 20 years ago. I was their attorney at the time when I practiced law in Springfield.

Sam Chapman is the Chief Nursing Administrator—I had to look twice; Sam is a nickname, obviously—Administrator for the Bureau for Children with Medical Handicaps of the Ohio Department of Health. She gained valuable firsthand experience as the former Director of the Fairfield Visiting Nurses Association in Lancaster, Ohio. Mrs. Chapman is testifying today as the national secretary on the board of the National Association for Home Care, the Nation's largest trade association representing the interests of home care agencies, hospices, and home care aide organizations. Thank you.

Mardell Bell is a member of Local 880 of the Service Employees International Union, and comes to us from Dolton, Illinois. We are glad to have you here. The SEIU represents over 175,000 home care workers and has compiled a survey on the effects of lack of insurance for home health aides in Los Angeles. We thank you all for coming to this hearing, and to show you the process of the Senate and this Subcommittee, it is customary for us to swear in all witnesses. Therefore, I ask you to stand and raise your right hand. Do you swear that the testimony you are about to give before this Committee is the truth, the whole truth, and nothing but the truth?

Ms. HAYWARD. I do.

Ms. MINTZ. I do.

Mr. STEARNS. I do.

Ms. SIMS. I do.

Mrs. CHAPMAN. I do.

Ms. BELL. I do.

Senator DURBIN. Let it be noted for the record that all the witnesses answered in the affirmative and therefore will be allowed to testify. Ms. Hayward, I am going to ask you if you would limit your oral statement to 5 minutes. Your complete written statement will be made part of the record, and then we can engage in dialogue and questions. Please proceed.

TESTIMONY OF JANE HAYWARD,[1] DEPUTY DIRECTOR, RHODE ISLAND DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. HAYWARD. Good afternoon, Mr. Chairman. Thank you for the opportunity to speak with you today about a Rhode Island strategy to support caregivers.

In particular, child care workers. Let me tell you a little bit about the background and how we came to do this. With the advent of welfare reform, Governor Lincoln Almond and the Rhode Island General Assembly exercised great leadership and took very positive and proactive steps to provide low-income families with the support they need to be successful in the work place, and those supports, as we defined them, were child care and health care.

The Family Independence Act of 1997, which was Rhode Island's welfare reform statute, had two pieces to it that are pertinent to our discussion today. The first established the Nation's only entitlement to child care for families who are trying to balance work and family responsibilities as they transition to self-sufficiency, and the second broke new ground. It was the implementation of fully-paid health insurance for certified family providers and for their families. Additionally, the Starting RIght initiative, which is Rhode Island's early care and education initiative, extended support of health care coverage to employees of center-based programs.

In addition, at the same time, similar gains were being made in increasing access to health care by expanding eligibility to working parents up to 185 percent of the Federal poverty and to uninsured children in families with income up to 250 percent of poverty. What were we trying to achieve when we decided that health insurance was a good tool to help us in the child care industry?

We wanted to increase the capacity within the industry, as welfare reform, we knew, would bring additional demands on an already-strained industry. We also wanted to try and help to stabilize the workforce in the child care industry. As you indicated, Mr. Chairman, that turnover is very high. Finally, we wanted to provide access to health insurance to an industry that was underserved, if served at all. Low wages escalating health insurance premiums make the cost of health insurance prohibitively high for both certified family providers and many center-based programs. So how does it work? What do we do?

Both child care centers and family providers must hold licensure and they have to make a commitment to serving low-income children. Certified family providers must earn $1,800 within a 6-month

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[1] The prepared statement of Ms. Hayward appears in the Appendix on page 24.

period, taking care of youngsters who receive subsidy through our child care assistance program. They are allowed to maintain that coverage as long as they continue to maintain the minimum number of youngsters in their care. That coverage is provided through the RIte Care program, which is Rhode Island's managed care Medicaid program. In addition, licensed centers must maintain that same commitment to low-income youngsters, and they must maintain 40 percent of their total enrollment, being youngsters who receive subsidy through child care assistance.

Coverage for them, however, is provided in a different way, and we use a premium assistance strategy to cover them and offer 50 percent of the cost of their premium to the center. That allows them to continue to stay in employer-sponsored insurance. It is good for the health insurance market. It is good for the center and it is certainly good for the employees and their families. The cost of providing these health care options for State fiscal year 2001 was $1.3 million, and that is in a $66 million child care program, all State dollars.

I would imagine that one of your questions would be whether we think we got a good return on our investment. Currently, we have 267 certified family providers and 237 of their youngsters enrolled in RIte Care. In addition, we have 56 centers who are receiving premium reimbursement covering 587 staff and their families. We increased capacity among licensed and certified providers by 31 percent. Family provider placement opportunities increased by 43 percent; centers increased by 12 percent, and we doubled the number of subsidized children from 1997 to 2002. We think we made a great investment.

We also believe that this model can work to benefit other caregiver groups. Fully paid health insurance could clearly support personal care attendants, readers for the blind, interpreters for the deaf. All of these groups are undervalued, underpaid, and have high turnover. Again, they are very similar to family child care providers. In addition, Rhode Island has established recently a premium assistance program through its Medicaid and SCHIP programs, and what we are doing is aggressively marketing the agencies that are caregiver agencies—nursing homes, home health agencies, residential treatment facilities, group homes—in an effort to try and assist them with their health care. But to date, we have been paying for it alone.

Our suggestion to the Subcommittee is that this is a wonderful tool to be able to build capacity within these kinds of industries and to support the caregivers. We do think, however, that States who may want to use this tool to support their caregiving industries could benefit from some flexibility under Federal programs. For instance, for those who are working in industries receiving Medicaid or SCHIP financing, flexibility for health insurance premium as a cost of care for those who would not normally be eligible for Medicaid would certainly be a help, whether that is in a matching rate or whether it is in a grant activity. Similarly, the flexibility to use the child care development block grant and to have the cost of health insurance be an allowable cost would significantly increase other States' ability to model this program. We think this has been a tremendous success. We would recommend it to other

States, and I thank you for your time, Mr. Chairman, and I would be happy to take any questions.

Senator DURBIN. I will have some questions, too, and I thank you for your attendance here today. It really is a good place to start in this hearing, because Rhode Island has done it, and you can tell us what your experience has been. The statistics are very impressive.

Suzanne Mintz.

TESTIMONY OF SUZANNE MINTZ,[1] PRESIDENT AND CO-FOUNDER, NATIONAL FAMILY CAREGIVERS ASSOCIATION

Ms. MINTZ. Mr. Chairman, thank you for this opportunity. My name is Suzanne Mintz, and I am the President and Co-founder of the National Family Caregivers Association—not alliance—and I am myself a family caregiver. 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.

NFCA's members tend to be heavy-duty caregivers, meaning they are providing extensive hands-on care on a daily basis, helping loved ones dress, bathe, toilet, etc.

Senator DURBIN. Excuse me. Would you pull the microphone down just a little bit? Thank you.

Ms. MINTZ. For three-fifths of these caregivers, caregiving is the equivalent of more than a full-time job. Although the term "family caregiver" is now understood by many, I do not believe that the role of family caregivers in society is thoroughly appreciated. Family caregivers are literately underpinning our health care system. The vast majority of care provided to chronically-ill, disabled individuals, or the elderly is provided by family caregivers. Approximately two-thirds of seniors rely solely on family or friends for their care, without any support from the formal system.

Caregiving is everywhere. Seventy percent of the population says it is either a caregiver now or knows someone who is a caregiver. The conservative market value of services provided by family caregivers was estimated to be $196 billion, and that was in 1997. The market value at the time for professional home care and nursing care services combined was valued at $115 billion. As the population continues to age, as medical science continues to extend the lives of persons with chronic illness, and as health care containment policies send people home from hospitals sooner and in need of more care than ever before, you can expect to see an increase in the number of people who will need to be cared for.

Caregiving and its impact is the issue of our time. caregiving is often a continuum. For many, it begins by providing a small amount of assistance to an aging parent or spouse with a degenerative disease, and then over time becomes a 24–7 experience. For others, intensive caregiving begins very suddenly, as when a baby is born severely ill or when a loved one is in a terrible car accident or has a massive stroke. Listen to these comments from a family caregiver in Rockville, Maryland: "I am a 35-year-old mother of a

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[1] The prepared statement of Ms. Mintz appears in the Appendix on page 32.

5-year-old, severely disabled daughter, Kaylee. She suffers from a rare genetic disorder. Kaylee is given 13 medications a day, just so she can survive. She is fed via a G-tube. She requires 24-hour medical care."

The physical and emotional impact of intensive family caregiving has been well-documented. These caregivers are known to suffer more depression and other stress-related ailments than the general population. In a NFCA member survey, 61 percent of caregivers reported depression, 51 percent sleeplessness, 41 percent back problems. A study published in the Journal of the American Medical Association showed that elderly spousal caregivers under stress have a 63 percent higher mortality rate than non-caregiving spouses. A caregiver in her 80's from Champlain, Illinois, puts it this way: "I am just stressed out. I have come to a point where I just really worry all the time. I am exhausted."

Caregiving is expensive. Families in which one person has a disability and needs help with daily living activities spend two-and-a-half times more out-of-pocket on medical expenses than families without a disabled person, 11.2 percent of income. Thirty-five percent of the general population has an income of less than $30,000. Among caregiving families, that percentage rises to 43 percent. Caregiving literally extracts a price from caregiving families. The majority of family caregivers are employed, nearly 64 percent, but over a third have reduced their work hours or taken time off because of caregiving responsibilities.

Six percent of those caring for the 50-plus population have left the workforce because of their caregiver responsibilities. Adding to the problem, family caregivers who leave the workforce not only lose their paychecks, they lose the future benefit of the additional Social Security credits they would have earned.

Although I am not familiar with any studies that document how many caregivers have lost their group health insurance because they have left the workforce, anecdotal information from NFCA members suggests that for some caregivers that is, indeed, the case. This is a sample of what we were told when we sent out an E-mail asking that question: "My husband's job 'disappeared' after his stroke in 1998 and with it our medical coverage." "I had to give up both work and health insurance for a period of 6 years due to caregiving responsibilities." "I have been a caregiver for my mother and aunt, both in their 80's, since 1991." "I had to quit my job last year when my mother had another heart attack." "I lost health, dental, vision and disability insurance, plus, pension and deferred compensation." "I am presently retaining my health insurance through COBRA, but it costs me $304 a month and it will run out on January 1, 2002."

It is clear that family caregivers are making a tremendous contribution, not only to their individual loved ones, but to American society as a whole, and some of them are doing so at a huge physical, emotional and financial cost. If we expect family to provide high-quality care for chronically ill, disabled or aged loved ones, then the work that family caregivers do, the uncompensated work of caregiving that is done with feelings of love and out of a sense of duty, needs to be valued and supported in direct and meaningful ways. Without family caregivers, our current health care system literately could not function. The length of hospital stays, the need for institutionalization and professional home care services would expand significantly if families were not bearing the burdens of extensive caregiving.

Therefore, it is in the government's interest to help ensure the health of family caregivers by providing for a high-quality health insurance to the caregivers who need it. It is in the government's interest to support the work of family caregivers and create a more equitable balance between what a family is expected to do on its own and what is more the province of professional providers. If a family caregiver gets sick or dies, who, then, will care for their loved one? It is less costly, more humane and better policy to protect the health of family caregivers while we can, providing them with quality health insurance is one of the ways to do that.

Thank you, Mr. Chairman.

Senator DURBIN. Thank you. That was an excellent statement. James Stearns.

TESTIMONY OF JAMES STEARNS, ESQ.,[1] PAST PRESIDENT AND CURRENT BOARD MEMBER, UNITED CEREBRAL PALSY ASSOCIATION

Mr. STEARNS. Good afternoon, Mr. Chairman and Members of the Subcommittee. I am James Stearns, current board member and past president of the United Cerebral Palsy Association. I appreciate the opportunity to testify before you today on the importance of health insurance and other compensation for direct support attendants for people with disabilities.

I personally have the condition of cerebral palsy. I have spent time in a rehabilitation facility and I have been helped significantly by direct care attendants. My remarks today will be based on my experience and also the experience of many individuals with disabilities that we have surveyed throughout our organization. Direct support attendants assist people, as many of us know, with disabilities in daily activities, such as eating, dressing and using the bathroom. These attendants are truly essential to the ability of hundreds—Mr. Chairman, hundreds of thousands of people with disabilities—to live as independently and as productively as possible.

There is a national crisis today, Mr. Chairman, which we know you recognize, with these services because Medicaid and other third-party programs simply are not keeping pace with the costs necessary to provide quality attendant services. And this crisis, unfortunately, despite the efforts of many people, is getting worse. Mr. Chairman, as you probably know, the required number of personal care attendants is expected to grow from 256,000 in 1998, to 374,000 in the year 2006, according to a recent Labor Department study. Even with the current demand, as indicated by these numbers, however, our UCPA affiliates are unable to recruit and retain enough personal care attendants.

These affiliates report to us nationwide job vacancy rates as high as 35 percent, and few are accepting new clients for attendant services. This means, Mr. Chairman, that literally thousands of peo-

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[1] The prepared statement of Mr. Stearns appears in the Appendix on page 37.

ple—I repeat that, thousands of people with disabilities are languishing in costly government-funded institutions and thousands more are living at home with elderly parents who are increasingly unable to take care of them. This is a shocking waste, Mr. Chairman, of both human capital and Federal tax dollars.

We ask the question: Why is there an attendants shortage? Medicaid and other third-party payers usually do not cover the necessary costs of employing attendants. Private health insurance seldom covers any attendants services, while Medicaid often pays very low rates. For example, Medicaid attendant reimbursement rates were as low as $5.24 an hour in California in 1999; in the State of Maine, $6.25 an hour; in Michigan, $6.50 an hour. All these figures, Mr. Chairman, come from a study funded by the Federal Department of Health and Human Services.

Mr. Chairman, in view of these low payments, it is simply not surprising that the national average wage for personal care attendants was $7.72 an hour in 1999, according to Labor Department studies. If you do the math, Mr. Chairman, that comes to a full-time annual income of $16,060, which, as we understand it, is $969 below the 1999 poverty rate for a family of four—$969, I emphasize, below the poverty rate in 1999 for a family of four. Despite these problems, Mr. Chairman, as you know, most attendants are highly dedicated to the people they serve, but they cannot ignore the economic reality of low compensation. Indeed, compensation is a key factor in aide turnover, according to an HHS-funded study in California last year. So it is not surprising that our UCPA affiliates nationwide have a turnover rate of approximately 100 percent. I did not misstate that—100 percent, Mr. Chairman, per year, for direct support workers and other providers that speak to us have similar rates.

Mr. Chairman, we emphasize to you today as a national organization that the role of these attendants is critical to the well-being of individuals with disabilities. For example, as you know, if medications are not properly administered to a person, that person's very life may be endangered. Some of the things, and these are just some of the things, anecdotal examples, Mr. Chairman, that an attendant needs to be trained for include, besides administering medicine, which we spoke to a moment ago: Transfer and lifting; showering; dressing; feeding; catheterization; disability sensitivity; punctuality and general people skills; and cooking.

Let me share with the Subcommittee just a few anecdotes from members of our organization. One attendant, for example, mixed the peas with the applesauce, because they simply did not seem to know any better. They simply had not been trained. Another asked a person with a disability if he needed to turn on the stove in order to cook dinner. Again, we are not being at all critical of the attendants, that is just the problem with training. Another aide, when asked to be on time, said “find another attendant.” Serious consequences flowed from that incident. If the attendant does not show up on time, for many people with disabilities, that means they cannot get out of bed. They cannot even take care of bathroom needs. And if the person is late for a job, the person with a disability, because of the attendant's tardiness, that person's job can be put at risk.

We found, Mr. Chairman, that improper feeding methods can lead to choking, and improper lifting may mean that the person with disabilities, who obviously already may have some frailties, can be dropped. If the attendant hurts himself or herself through improper lifting, then the attendant can become suddenly unavailable to help that particular client. If an attendant, conversely, is unavailable for any reason, their client's ability to get out of bed, go to work and keep appointments may become impossible. Other examples, Mr. Chairman—an attendant may need to drive a car, travel with their client, and know what to do in emergency situations.

In addition, personal security is an issue with high turnover rates. Caregivers may be given a key to the home and the car, access to bank accounts and access to the telephone. In the worst of all cases, the caregiver relationship can create a situation where the person with disabilities is vulnerable to abuse until they are able to get to a place of safety. High turnover rates, Mr. Chairman, can also mean that the person with disabilities has to constantly retrain attendants. The training period means that everything takes longer, and this has a ripple effect through the day of the person with disabilities.

Mr. Chairman, studies have noted, as I said above, that 45 percent, for example, of Los Angeles County home care aides lacked health coverage last year, while 60.6 percent of California personal care aides statewide lacked it in 1999. Although millions of other low-income people also are uninsured, the aides' lack of health coverage has two serious consequences which we ask you to take notice of today. First, people without insurance are less likely to obtain timely medical treatment. This leads to more serious conditions and more time lost from work. Second, Mr. Chairman, when an aide has a communicable disease, delayed treatment increases the risk of transmitting that disease to the person served by the aide.

UCP believes, Mr. Chairman, that additional steps, besides the insurance question we are talking about today, need to be taken to solve the aide crisis. We support legislation to increase Medicaid State reimbursement rates to a specified target amount, such as, for example, the States' average State institutional aide wage rate. Under this approach, Mr. Chairman, the added cost would be 100-percent funded through an enhanced Federal Medicaid contribution.

Mr. Chairman, in conclusion, UCP strongly supports your draft bill to provide State formula grants to offset all or part of the cost of caregivers' health insurance. We believe the enactment of your bill is one of several critical steps that should be taken immediately to prevent the imminent collapse of community-based aide services for people with disabilities. Mr. Chairman, our organization thanks you for your time, your commitment and the commitment of your staff. We stand forward to help in any way possible and to answer whatever questions you may have for us.

Thank you.

Senator DURBIN. Thank you, Mr. Stearns. Ms. Sims.

TESTIMONY OF YOLANDA SIMS,[1] HOPE SCHOOL FOR THE DEVELOPMENTALLY DISABLED, SPRINGFIELD, ILLINOIS, MEMBER, AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES

Ms. SIMS. Good afternoon. My name is Yolanda Sims. I want to thank you, Senator Durbin and the Subcommittee, for letting me speak today about the importance of health insurance for direct care workers. The Caregivers' Access To Health Insurance Act of 2001 would help thousands of caregivers and their families get affordable health care. Thank you for introducing this legislation, Senator Durbin.

I am a member of AFSCME Council 31, Local 2481 in Springfield, Illinois. I am also a member of our collective bargaining committee. I am proud to say that we in AFSCME are working hard to improve wages, benefits and working conditions for caregivers. We won our fight for better wages for direct care workers who care for people with disabilities. Employees campaigned to give caregivers a $1 per hour raise. Although we have not received it yet, that will bring the starting wage at Hope School to $9.24 an hour.

I am a lead teacher aide at the Hope School in Springfield, Illinois. The school provides education and other services for children and youth with multiple disabilities ages 6 through 21 years old. I have been with the school for 5 years. My husband, Robert, works at the school, as well. We have two children; Nathaniel, 8 and Natalie, who is 5. My employer's office has health insurance. My husband and I are covered. We have to pay $20 per month taken out of each of our paychecks to pay for our individual premiums, but family coverage costs $260 a month. That is 12 percent of our take-home pay. On top of that, there is a $250 deductible and a 20 percent co-pay.

This could really put you in a bind when you have to pay rent, utilities, have reliable transportation so you can get to work, and other costs of living. When birthdays and Christmas comes up, I have to do overtime just to cover them and that overtime is not always available. Even though I know it is important for my kids to be covered, my husband and I just cannot afford it. The kids used to be in Kid Care, but when I got married they were disqualified because our combined income was too high. Anyone who has raised children knows that even if they are usually healthy, things happen. But I cannot afford to buy family coverage that is offered by my employer. I cannot afford to take them to the doctor. So when my son falls and needs stitches, I take him to the emergency room. When one of my children starts to get sick, I go to the drug store and I buy vitamins and whatever over-the-counter medicines I think will help them. They do not see a doctor unless it gets really bad. Then I take them to the emergency room. Then the hospital sends me a bills that I pay off as much as I can.

Two-and-a-half years ago, my husband had kidney stones. He had to have surgery. Even though he has health insurance, it did not cover everything and we are still paying it off. Little by little every month, we pay what we can. Balancing the cost of daily living and health care costs can be very stressful. You do all you can

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[1] The prepared statement of Ms. Sims appears in the Appendix on page 42.

to keep your children from getting sick, but things happen that are out of your control. Recently, my daughter caught poison ivy. I tried to treat it myself, but I had no knowledge of how poison ivy looked. I thought she had the chicken pox and treated it as such. But it just keep getting worse and spreading. Finally, I had to take her to the emergency room and that is when they informed me that it was poison ivy. By this time, she needed treatment and a prescription that could have been avoided. Since I did not recognize it right away, I had to pay for the prescription, and I now have other medical bill to pay off on top of the huge pile of medical bills that I already have.

I feel like if I had affordable coverage, I could have a regular doctor for my kids, a doctor who is familiar with them and could have helped them without me having to go to the emergency room. One thing that I feel really bad about is that I know my son is going to need braces, but we do not have medical coverage. I do not think we are going to be able to pay for it ourselves. I have to live with the thought every day that if I do not figure out something soon he might have permanent damage to his teeth. I believe that if all workers at my school had health insurance, they would be able to be more effective with the kids we work with.

First of all, when a family member is sick, it makes you really stressed out if you are not sure if you can pay to see a doctor. So you worry about how long should I wait before going to the emergency room? Will they get better on their own? When you are stressed, it is harder to really focus on the kids you work with. Another thing is that at my school there is a lot of turnover. One of the reasons people leave is because the pay and the benefits are not good. Turnover is rough on consistency with the kids and staff. They regress in their programs. They start to lose skills. Every time a new staff member comes, it is like starting all over again.

The youth begin to act out with people they know. Instead of helping them to reach their fullest potential, we end up just babysitting. This can be frustrating to staff members who want to see the children succeed. If we had affordable health insurance, I think more people would stay. I think there should be more public funding of insurance. I know that when my kids need care and we use the emergency room, I am taking a doctor's time away from a real emergency. If more affordable health insurance were available, I would use it. My kids could have their own doctor and have regular checkups and maybe we would not be spending all of our money on bills from the ER.

Thank you for this chance to tell you how important affordable health insurance coverage is for caregivers and their families.

Senator DURBIN. Thank you, Mrs. Sims. Mrs. Chapman.

TESTIMONY OF D.J. (SAM) CHAPMAN,[1] CHIEF NURSING ADMINISTRATOR, BUREAU FOR CHILDREN WITH MEDICAL HANDICAPS, OHIO DEPARTMENT OF HEALTH; NATIONAL SECRETARY, NATIONAL ASSOCIATION OF HOME CARE BOARD

Ms. CHAPMAN. Good afternoon. I have a career history as a home health administrator, first, for Children's Home Care Services,

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[1] The prepared statement of Ms. Chapman appears in the Appendix on page 45.

which is located in Columbus, Ohio, and until recently for the Fairfield Visiting Nurses Association, which is a department of Fairfield Medical Center, and I have offices in Lancaster, Logan and McConnellsville, Ohio. On August 13, I will be, again, in my full-time position with the Ohio Department of Health, Bureau for Children with Medical Handicaps, as the chief nursing administrator. In addition, I have the privilege of serving as the secretary to the National Association of Home Care Board, and in this position I represent the views of 4,000 home care agencies nationwide. I am also the primary caregiver for my 83 year-old diabetic mother.

Throughout my career, I have dedicated myself to the provision of quality care to children with special health care needs and to the fragile elderly requiring home health care. I also have worked to support the workforce of caregivers, the dedicated home health aides who are the backbone of the home care industry, because I myself began my career as a nurse aide. Home health aides provide the most intimate care to our elderly and medically fragile children, bathing, feeding, wiping the drool from their mouths, offering encouragement to recovery stroke victims and assisting children confined to a wheelchair get ready for school each morning. Without the help of an aide who arrives at 5 a.m., a patient of mine, a child, could not receive the education he has a right to.

I am here today to address the difficulty that home care agencies are facing in attempting to secure sufficient staff to meet the growing demands for home health aide services. It is my belief, and that of others in the industry, that expanding the availability of health insurance for caregivers and their families is the key ingredient to the recruitment and retention of this workforce.

The home health aide profession is dominated by women who, at best, have a high school education. The majority are single heads of household with school-age children or younger, and the average age is around 40. They are the most dedicated individuals that I have had the privilege to work with. The staff working for the VNA that I am the administrator for, had the opportunity to purchase family health care coverage for $42.60 a week, or $2,000 annually, which was about 30 percent of the total health care premium. My agency had the luxury, because we were associated with a hospital, to be able to provide these benefits to our staff. Most agencies, however, in our State require 50 to upwards of 100 percent total employee contribution.

Over 20 to 30 percent of aides in our agency and statewide choose not to purchase insurance from the agency. They elect not to purchase these services because they need to be able to pay housing, electricity, be able to buy school supplies for their children. We have one of the best plans and our staff still cannot afford to purchase this health care insurance. The challenge of providing a livable wage and benefits to this caregiving staff is one of the biggest, if not the biggest, challenge facing home care agencies, no matter what their organizational structure is. As I previously said, the FVNA, due to its affiliation with the parent hospital, was able to offer health insurance coverage to our employees. However, the ability to offer and the employee's ability to select and afford this benefit are two entirely different questions.

For the majority of agencies, they have seen their health insurance costs raise at the rate of 18 to 20 percent a year. They have been forced to choose between offering salary increases or increasing the employees' contributions to cover this rising cost of health insurance. Agencies have also witnessed the effect of rising gasoline prices. They have been forced to increase their mileage reimbursement to staff or they face the loss of the staff. For one northern Ohio home care agency, this mileage increase added $200,000 to their annual expenditures. This expenditure was just so that our aides could continue to provide services to the patient that we care for.

There have been no increases in funding for services and agencies have been required to carry the burden of unfunded regulatory requirements. All of the above, plus low unemployment rates, are leading to the next crisis in health care, the patient access crisis. Agencies cannot provide needed care if they do not have the aides to provide the care. To assist in stopping this crisis, I would encourage Congress to continue to expand access for caregivers to health insurance by initially providing Federal subsidy for health insurance for caregivers; second, by mandating Medicare, Medicaid and other Federal programs that finance home care and hospice services, to adjust reimbursement rates to allow for appropriate benefit levels for staff; third, requesting governmental studies related to the lack of health insurance coverage for caregivers and what can be done to overcome this problem; and finally, reducing Federal unfunded regulatory burdens and costs that home care agencies have been forced to comply with in order to continue to provide services to their patients.

If the above recommendations were implemented, then maybe no other home care administrator would be forced to make the hard decision to close their McConnellsville office, as I was. I had to close an office where the unemployment rate was one of the highest in Ohio, in a location that is underserved, economically depressed, and where 75-plus patients now have an access to quality health care. Mr. Chairman, on behalf of the members of the National Association of Home Care, the elderly, children with special care needs, and more importantly, for the home health aides that I represent, I thank you for your gift of time, and for holding this hearing on this important health insurance issue for caregivers.

Thank you.

Senator DURBIN. Thank you for your testimony. Ms. Bell.

TESTIMONY OF MARDELL BELL,[1] LOCAL 880, DOLTON, ILLINOIS, SERVICE EMPLOYEES INTERNATIONAL UNION

Ms. BELL. On behalf of my fellow home care members of Local 880 and SEIU, I thank you for this opportunity to testify before the Subcommittee. I find it ironic that so many health care workers like myself do not have health insurance. We especially appreciate Senator Durbin's interest in the issue of health care for home care workers, and his efforts to address the problem of uninsured caregivers.

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[1] The prepared statement of Ms. Bell appears in the Appendix on page 53.

The Caregivers' Access to Health Insurance Act brings much needed assistance to home care workers and other caregivers. SEIU represents 185,000 home care workers throughout the United States, and Canada, including 13,000 in Illinois. Home care workers provide essential services to people with disabilities of all ages.

I want to tell you something very personal about me and my client, some of the things I do to assist him. My client is 48 years old. He cannot tie his shoes. He cannot write his name. He cannot make up a bed. He cannot cook for himself. So I cook for him. I do his banking for him. I take him to the grocery store, him and his mother—his mother is 82 years-old. I take her to the store, also, and I also take them to the doctor. I also go and get their prescriptions. I go and—whatever they might need for clothing—I go and assist them. Whatever programs she might need to go to public aid, I take them there. I cook all of his meals. I iron all of his clothes.

I was thinking that, with all the things I do—he is the only one. He is happy. He appreciates me. I turn on music for him and I say, "Come on, Clarence, let's dance." We have fun. We dance. I say, "Come on, let's go for a walk." He does not get out to do exercise, so I walk him around the block. We will walk around to the corner store, so I can get him to be out in the sunshine. He likes to eat. He always offers me his food. "Do you want some of this? Do you what some of that?" He asked me once, playing with me, he said, "What is your telephone number?" I said, "Are you going to call me?" He said, "No." I said, "Well, I am not going to give it to you." We have a good relationship.

I love my job and I love what I do. I am almost like a poster child for home health care. I love my job sincerely and my client loves me. Every day, it makes it worthwhile just to come to see him smile and have him say, "Where are we going to go? Where are we going to go?" I love it when he tells me he wants to go. He loves to ride. He loves to get out in the sunshine.

But, recently, I was sick. I have been sick for 4 years, and I have been doing this for 4 years and I did not have health insurance. I have three daughters. I have a husband and my husband's job closed down. It moved to Atlanta. So I am the only breadwinner right now. So on my $7 an hour—I work 7 days a week, 7 hours a day, because he needs that kind of care and my family needs that kind of care. I have to be the sole breadwinner at this particular time, and what I like is that even though I went 4 years without medical care and attention, I was a trooper. No matter how sick I was feeling, I said I just have a cold—I said I would just take the medication, I will be OK. I developed coughing real bad.

Finally, I got so sick that I had no choice but to go to the doctor, to the emergency room. I found that I was diagnosed with asthma, severe asthma, severe bronchitis and sinuses. In my client's house, to get to his bedroom, it is 16 steps going up. To get to the basement, it is 12 steps going down. So I am up and down these stairs all day long. If anybody ever had a problem with breathing and going up and down stairs—because when I mop the kitchen, the things I need to clean the kitchen with, the floors with, they are kept downstairs. When I wash clothes, they are downstairs. Upstairs needs to be vacuumed. The beds need to be made. On the other floor, we have to cook dinner. So I am up and down and in all parts of the house.

Medical Care is so important, I cannot afford it. I need it, but I cannot afford it. With my job that I do, I cannot even take time to go to the doctor. I have medicine, but when I do go to the county hospital, I still have to pay. When I get a prescription, I have to wait 7 days and I hope I do not have an asthma attack. Without the medication, I cannot do my job wholeheartedly, happily, without being worried. It brings stress to do this job without the proper medication. But with the medication, I am happy. I am alert. I am fun. I want him to have fun. I enjoy doing my job.

Sometimes with my family, they miss me with these hours. People say, “Do something else,” but I love my job. When you love what you are doing—why should I quit my job when I love taking care of people with disabilities? If it is not me, it would be someone else. We cannot provide health care—health care is available. There are solutions and they are available, and through this program, I believe that we can do this. Thank you.

Senator DURBIN. Thank you. Ms. Bell and Ms. Sims, I think in your testimony you put a face on the uninsured people in America, your children and you personally and your family, uninsured. I think many people mistakenly believe that those who are uninsured just sit at home and do not do anything. You get up and go to work every day, tough jobs, that a lot of people would not do, and you do and do well.

Hope School, I know it started off as a facility for children who were blind and had some other major handicap, and I know it now involves a lot of other disabilities. That is hard work. Ms. Bell, as you tell the story about your personal dedication, Clarence is lucky to have somebody like you. So is his mother, and we are to be thinking about this as we put this issue in perspective.

When I first started looking at this, Ms. Hayward, I thought to myself that it would be so simple just to mandate health insurance coverage and to say you have to provide health insurance coverage for daycare workers, and people like that. But you know what that is going to do, it is going to raise the cost of daycare, and families are already struggling to pay for daycare. So I thought to myself why don’t you create categories of people who are so important to us, who are really irreplaceable, and say these people deserve to have health insurance. Rhode Island made that decision. I ask you, as a result of it—in your testimony, you have alluded to some of the statistics, but over the last—has it been 4 years since it has been in place?

Ms. HAYWARD. Yes, since 1997, Senator.

Senator DURBIN. What about the turnover rate now in some of the covered jobs that now have health insurance through Rhode Island’s own program?

Ms. HAYWARD. We believe that the turnover rate has decreased; however, we attempted a survey as part of our market-rate survey which we do every 2 years to determine what the reimbursement rate will be for child care providers, and the data was really very unclear. I am not sure whether we asked the questions in the wrong way, whether the questions were misleading or confusing, but the data that we got back was not helpful to us. We are in the process of trying to revise that and look at it again, but clearly what we are seeing is—anecdotally, we are hearing from folks that they are able to retain employees longer. By participating in paying the premium, we are freeing up dollars within those centers that can go to increased wages, which also helps to stabilize and fortify the industry. So we think that there are a number of ways that we have gone at it, and we are hopeful that this fall we will have some data that will support it more clearly.

Senator DURBIN. Does Rhode Island pay for its program through general revenues?

Ms. HAYWARD. Yes, it does.

Senator DURBIN. Do you provide Medicaid coverage or is it private coverage?

Ms. HAYWARD. In Rhode Island, for families and children and for child care providers, that is one and the same. Our Medicaid managed care program, RIte Care, purchases health insurance through the three available commercial plans available in Rhode Island. So our Medicaid beneficiaries, as well as the family child care providers, will have an insurance card just like you or I would.

Senator DURBIN. Does it cover dependents, as well as the workers?

Ms. HAYWARD. Yes, it does.

Senator DURBIN. That is quite a plus; isn't it, Ms. Sims? Let me ask you about the type of coverage for these workers as compared to say, State workers, State employees.

Ms. HAYWARD. The coverage is comparable. The coverage is comparable.

Senator DURBIN. In terms of cost and cost containment, can you tell me what Rhode Island is doing to deal with that?

Ms. HAYWARD. Well, we have two goals; one is to continue to decrease the number of uninsured in the State; Rhode Island has among the lowest. In some surveys, it is indicated that we are the lowest rate of uninsured in the country. We have a commitment to continuing to lower that. There really are two ways to go at it. One is to do it through a Medicaid-like buy-in or to do it through employer-based insurance, and we think there has to be a balance. To the extent that we are able to leave people in employer-based insurance, we think that is a better choice. For our family providers, that was not an option, but for our center-based providers, it is an option and it really falls into the philosophy that we have, that we need to be able to stabilize that market, as well, and we are not doing that if we are pulling folks out of it.

Senator DURBIN. Ms. Mintz, what is the average age of family caregivers?

Ms. MINTZ. The average age of a caregiver who is caring for somebody over the age of 50, is 47, so very much in the span of work years.

Senator DURBIN. Is that age going up or can you tell me if there is any trend line, in terms of these family caregivers?

Ms. MINTZ. I do not know so much if there is a trend of the age of caregivers necessarily going up across the board, but because people are living longer and people over 85 are the fastest-growing segment of our population, you have situations now where we have the old caring for the even older. In situations where you will have spousal-caregiving, in that sense, the age of caregivers is going up.

Senator DURBIN. And I would imagine that if some of these caregivers have reached Medicare eligibility age, they have coverage.

Ms. MINTZ. Yes.

Senator DURBIN. So it is basically those who are pre-Medicare eligibility that we are focusing on.

Ms. MINTZ. Yes, and what we were just finding in the information we were getting back in response to the E-mail that we sent out, is that it is very much those people who are in the middle who would normally be part of the workforce, who had to leave the workforce or cut back, or who are in part-time jobs in the first place and are not getting the insurance at all. That really is largely where those gaps are for the folks who often are forgotten because they are not eligible for any particular programs.

Senator DURBIN. Thank you.

Mr. Stearns, one of the things that I found interesting when I met with the disabled community in Springfield was how vulnerable people with disabilities are when they absolutely, positively have to have a caregiver. They literally get out of bed in the morning to be able to do the basic things we take for granted every single day, and with that caregiver, for many of them who could kind of unlock the door to their lives, they can come through that door and be very productive and do wonderful things, but they need that helping hand to get started.

They told me time and again about how tough it was to find that person. They are paying very little because it is an expensive undertaking. They are vulnerable many times to those who do not treat them well or steal from them or whatever it happens to be. I cannot imagine that feeling of vulnerability where you are literately dependent on somebody being at the door at the right moment so your day can start, and then your life is in their hands the entire day. I thought about that as I reflected on this bill and I thought all the more reason for us to really reward people who are personal caregivers to the disabled, so that they will stick with it. When I hear Ms. Bell's story about her commitment to her client, that is the sort of thing you are looking for; is it not?

Mr. STEARNS. That is absolutely true, Mr. Chairman. Let me speak from my personal experience, which goes back more years than I care to remember, but also from the experience of the surveys we have done when we understood you were looking into this issue, which we applaud. I cannot speak as eloquently as the individuals have here today, but I can tell you that when I was trying to get into the educational system, I was totally dependent on that person to help me get out of bed. If I got out of bed on my own, I risked injury and in a couple of cases, I tried to get out of bed on my own, did not do it terribly successfully, and ended up back in the hospital for awhile.

You hit it exactly, Mr. Chairman. If you cannot get out of bed in the morning, if you literately cannot go to another endeavor, then where is your schooling that we have very correctly put a lot of money and resources into it? Where is your employment? We have, as you know, been very proud to have many individuals with cerebral palsy and other disabilities working here in the U.S. Senate and the other body, the House of Representatives. Let's assume that the caregiver cannot get those people up in the morning. Your constituents and you, sir, need people to show up on time. As committed as you are to the issue, they still have got to show up on time to do the business, and you can take that employment discussion and translate it across.

So it is absolutely key, and that is what I think people miss. I do not mean to denigrate anybody in that chain of giving care to people with disabilities. Certainly people in the medical profession are very important, but if the job of the personal care attendant is so basic, as has been so eloquently stated today, that if you cannot get that done, it does not matter the quality of health care, if you cannot get there. It does not matter, sir, if you would come to us and give 10 jobs on your staff to people with disabilities, if we cannot get them out of bed to show up in the morning, you cannot employ them.

Senator DURBIN. So all of the Senators, Democrats, Republicans, who voted for the Americans With Disabilities Act and said we believe in equal opportunity, here is your first test, maybe not your first test, but here is a test.

Mr. STEARNS. A key test, that is exactly the issue.

Senator DURBIN. Mrs. Chapman, you said during the course of your testimony that I did not see in your printed statement—you said you thought this was the singlemost important thing, health insurance, when it came to home care.

Mr. CHAPMAN. You are right, Senator. What I have seen with the staff that has worked for me and with other administrators in other agencies, I feel that we cannot continue to provide service and we cannot provide access to care if we do not have the workers. If my workers are getting up at 5 in the morning to put somebody on the school bus and then turn it around because they cannot make enough money to provide just the basic needs to meet their families, let alone health insurance, and they are working 12-hour days or 10-hour days, and they can go to McDonald's and become a grill cook and make $10.50 an hour with benefits, what is the incentive, other than the dedication to taking care of people, there for them to continue to work in my field? To me, we talk about the crisis with recruiting home care nurses and the crisis in nursing, yes, that is absolutely true, but those nurses cannot even do their jobs if we do not have the support of the support people. So without an adequate livable wage and adequate health insurance to keep these workers healthy and on the job, there is no way I can continue to do my job.

Senator DURBIN. This is our second hearing since there has been a changeover in the Senate. The first hearing was on the nursing shortage. The premise of my hearing was what is going to happen to America when we ring for a nurse and no one shows up?

Mr. CHAPMAN. What is going to happen to our people at home when they ring for a home health aide to get them out of bed and no one shows up?

Senator DURBIN. This hearing complements that first hearing. We have got to be honest about this. If we want the kind of quality care for ourselves and the people we love, then we have to deal with it. Who had the quote in here from Rosalyn Carter? Was that in your testimony? Someone had a quote in here about who caregivers are.

Ms. MINTZ. That was in mine.

Senator DURBIN. Excellent. I recommend it to those who would look at the transcript here. If we are not caregivers today, we may be needing care tomorrow.

Ms. MINTZ. There are only four kinds of people in this world: those who are currently caregivers; those who were caregivers; those who will be caregivers; and those who will need care.

Senator DURBIN. Yes.

Ms. MINTZ. And I think that is very true.

Senator DURBIN. What a perspective that is.

Ms. Sims, $260 a month to cover your two boys?

Ms. SIMS. That is correct.

Senator DURBIN. What is your hourly wage at Hope School?

Ms. SIMS. $12.20 an hour.

Senator DURBIN. $12.20. So after you have taken out all the deductions, $260 a month or a little over $3,000 a year for that health insurance for you—that is a tough one. I can see it. As you describe your life and dealing with emergency rooms, that really tells the story about people without health insurance trying to cope and trying to get by.

Ms. Bell, your situation, too, dealing with asthma, which can really literately stop you in your tracks, in terms of whether you can help your client, the person you are trying to help each day—it has been a serious problem for you; has it not?

Ms. BELL. Yes, and it is very scary when you do not—I have $1,200 worth of medical bills that I still have not paid from going to the county hospital, which the asthma—they are checking to see if it has done any damage to my heart. I took an echocardiogram and it cost $400. This started in December 2000, so my credit has been ruined because it was either buy food or pay these medical bills. I love my children, so I have to pay these bills. It is very scary, but with the medication and with good health care, I do not even feel like I have asthma. I run with my kids. I chase Clarence and make him do things and up and down stairs. There is no problem, as long as you have—if you have got the right coverage of insurance, where I can see a doctor properly like I should, then it would be no problem.

Senator DURBIN. I want to thank you all for your testimony. We may submit some written questions. Here is what I am going to do. I am going to make a deal with you here. I am going to tell your story to my colleagues in the Senate. You need to help me. You need to reach out to the Senators who represent you in your home State and the people you represent here and let them know about the importance of this issue. I think this is one of those issues that can escape attention. It is never going to be on the front page of the newspaper, and yet, it is as close to home as our children and our parents and the people that we love. So I am going to do my best to spread this information across the Senate and increase the number of sponsors of this effort that I am going to be introducing in just a few days, but I need your help and your organizations'.

I am going to start with Rhode Island because they point with pride to what they have accomplished. I thank you for being here to let everyone know across the Nation who follow this hearing, that it can happen, it can be done. This is not some over-the-rainbow idea. It has happened and it really has made a difference in the State of Rhode Island.

For each of you, for the family caregivers, and Mr. Stearns, with the United Cerebral Palsy, and Ms. Sims from Hope School in Springfield, Mrs. Chapman, thank you, from Ohio, and Ms. Bell, you will be back dancing with Clarence pretty soon, and we thank you for coming here and making this hearing so valuable today. It will stand adjourned.

[Whereupon, at 3:35 p.m., the Subcommittee was adjourned.]

A P P E N D I X

PREPARED STATEMENT OF SENATOR CLELAND

I want to commend Senator Durbin and the other Subcommittee Members for conducting today's hearing on the critical role of nurses in the Federal health care system. Military and Veterans' Affairs (VA) nurses have played a critical role in my life, not only as life-sustaining givers of care, but also as givers of hope. When I meet with health care groups from Georgia and across the Nation, the increasing need for nurses is always a part of the discussion. At the June 14 Senate Veterans' Affairs Committee hearing on the looming nursing shortage, I emphasized an alarming statistic that the Federal health sector, employing approximately 45,000 nurses, may be the hardest hit in the near future with an estimated 47 percent of its nursing workforce eligible for retirement by the year 2004. Current and anticipated nursing vacancies in all health care settings are attributed to a variety of factors including more career choices for women and worsening work place conditions with mandatory overtime and increasing patient care workloads.

I believe today we are facing a more widespread and complex challenge with this nursing shortage and there are no quick fixes. Key to developing needed legislative initiatives and understanding this complex issue is the testimony we will hear today from our panelists. It is crucial that Congress help nurses continue to take safe and effective care of their patients and for us to assist health care facilities to recruit and retain needed nurses as one answer, I have introduced S. 937 which is a bill to amend title 38, United States Code, to permit members of the Armed Services to transfer their Montgomery GI Bill educational assistance to spouses and children and this assistance could be used for undergraduate or graduate nursing education. I have also introduced S. 1080, the Federal Nurse Retirement Adjustment Act which will allow Federal nurses in Federal Employee Retirement System (FERS) plans to retain unused sick leave in retirement calculations comparable to nurses currently in the Civil Retirement System (CRS) plan. I urge my colleagues to carefully consider the testimony of today's witnesses as they develop initiatives to help recruit and retain Federal nurses.

State of Rhode Island and Providence Plantations

DEPARTMENT OF HUMAN SERVICES
Office of the Director

JANE A. HAYWARD
Deputy Director

TESTIMONY OF JANE A. HAYWARD
DEPUTY DIRECTOR OF THE RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

Before the
UNITED STATES SENATE SUBCOMMITTEE ON OVERSIGHT OF GOVERNMENT MANAGEMENT, RESTRUCTURING AND THE DISTRICT OF COLUMBIA

Hearing on:

"Who Cares for the Caregivers?: The Role of Health Insurance in Promoting Quality Care for Seniors, Children and Individuals with Disabilities."

July 24, 2001

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Good Afternoon Mr. Chairman and Members of the Committee,

Thank you for the opportunity to speak to you today about professional care givers, their critical role in supporting the most vulnerable of our citizens -- children, elders, and individuals with disabilities -- and Rhode Island's unique approach to supporting them. I appear before you today as a representative of a state with a longstanding commitment to, and proven track record of, providing low income working families with the supports they need to succeed in the workplace.

The Rhode Island Family Independence Act of 1997 recognized the importance of access to affordable health care and child care for low income working families making the transition to economic self-sufficiency. Since then, Rhode Island has become the only state in the nation to establish that low-income families trying to balance the responsibilities of work and family are entitled to affordable, quality child care services. The Starting RIght Initiative, adopted in 1998 at the behest of the State's Children's Cabinet, reaffirmed and extended this commitment to include expanding access to developmentally appropriate, early childhood education and support services programs for young children at-risk and their families. In order to ensure that every child enters school ready to learn and leaves school ready to lead a productive life. Starting Right made improving the quality of child care a top priority. Similar gains have been made in increasing access to health care, both by expanding Medicaid eligibility to working parents (with income up to 185% percent of the FPL) and to uninsured children (from families with income up to 250% of the FPL). Rhode Island has become widely recognized for the innovative health care and child care programs it has designed in its effort to realize these commitments. The development and implementation of health insurance for child care providers is an illustration of one such program.

Child care professionals in Rhode Island and elsewhere have historically been undervalued by society even though they provide services that directly affect family strength and well-being, the healthy development of our children, and ultimately our nation's future in an increasingly competitive global economy. Those who care for this nation's most valuable resource -- our children -- are paid wages considerably lower than workers with similar credentials in other fields, have little job security, and often go without employee benefits, especially health care coverage. For example, the average wage in Rhode Island for child care center staff, including head teachers and administrators, is $7.28 per hour. National surveys indicate that family child care providers earn an average of $4.04 per hour. Not surprisingly, health coverage is a benefit well out of the financial reach of many center based child care programs and certified family home providers. Moreover, even when these providers make health insurance available to their staffs, low wages and escalating insurance premiums make the costs of coverage prohibitively high for many to purchase.

As a result, turnover among staff of child care centers and self-employed family home providers is very common. Over one-third of all child care providers leave their jobs every year.

The most qualified staff often move on, if reluctantly, to higher-paying jobs out side the child care profession that offer employee benefits and a greater sense of security, but far fewer rewards. Indeed, the available evidence shows that many dedicated and professionally trained early care and education professionals would prefer to stay in the field if their earnings and benefits packages were comparable to what they are offered elsewhere, for example in a public school system. Care giver turnover erodes the stability and consistency of child-care giver relationships and has a strong negative impact on children and families, both in the short-term and over-time. A recent study found that children in child care programs who developed closer relationships with their care givers had better skills in all significant school readiness domains when moving from preschool into elementary school.

In sum, we believe a strong system of high quality, affordable and accessible child care is critical to the success of welfare reform, a growing economy and most importantly to the well being and healthy development of all of Rhode Island's children. Making that system a reality in the State has been, and will continue to be, a challenge that requires innovative thinking and creative solutions.

Indeed, when Rhode Island initially made its commitment to provide families with child care assistance at the start of welfare reform, the existing child care system had insufficient capacity to meet the anticipated need. Recognizing this, Governor Lincoln Almond, and the General Assembly addressed the issue pro-actively.

State policymakers took the first step by increasing the rates paid in the Department's Child Care Subsidy System in order to recognize the value of the services provided by the child care industry and encourage qualified individuals to enter or remain in the child care profession. As of January 2000, subsidized child care rates in Rhode Island reached and are maintained at the 75th percentile of a bi-annual state-wide market rate survey.

To further increase the capacity of the system, Rhode Island broke new ground by addressing directly the lack of health care benefits for licensed and certified child care practitioners. Effective January 1997, the state became the first in the nation to implement a program of fully paid health care coverage for licensed family providers and their children through the state's RIte Care, Medicaid managed care program. To qualify for coverage as a family home provider, the child care provider must be certified by the State's child care licensing agency and receive at least $1,800 in a six month period as reimbursement from the Department on behalf of working families eligible for child care assistance. Once these requirements are met, the provider and his/her children are enrolled for coverage for a period of six months. Health coverage can be renewed as long as the provider cares for children receiving assistance at the minimum level required (i.e. $1,800 in a six month period).

As part of Starting RIght, Rhode Island's Early Care and Education Initiative, in January, 1999, the State extended support of heath care coverage to employees of licensed center based child care programs.

The purpose for this expansion in access to subsidized health coverage was not only to further increase the capacity of the State's child care system, but also, in keeping with the goals of Starting RIght, to create an impetus to improve the quality of available child care programs as well. It was the State's hope that assisting centers in paying the costs for health coverage would help them recruit and retain qualified child care professionals and free-up resources that could be re-allocated to early education and child care programs.

The health coverage for centers takes the form of premium subsidy in which the State reimburses the provider 50% of the health care insurance costs paid for each employee. In other words, the center is required to pay a share equal to the State's share of insurance costs. As in the family child care provider program, to receive health coverage, centers must demonstrate a commitment to serve low-income children enrolled in the Child Care Assistance Program. In this case, however, to obtain and retain coverage, children receiving assistance must comprise at least 40% of the center's total enrollment capacity.

What are the outcomes that we have seen as a result of our investment in the health care of child care providers?

Currently, there are 267 certified family providers and 237 of their children receiving fully paid health care through RIte Care. There are 56 centers covering 587 child care workers with the help of the 50% premium reimbursement for health insurance costs. The total investment in our child care workforce was $1.3 million in state fiscal year 2001, out of a total child care budget of nearly $66 million. There are 854 child care workers who have health care as a result of these initiatives. Since 1997, we have increased capacity among licensed and certified providers by 31%. In addition, placement opportunities in certified family home care have increased by 43%, with a corresponding increase of 12% in center based early care and education.

We believe that this has been a cost effective strategy to help fortify and stabilize the industry, and to expand the State's capacity to give support to the increasing number of low income families entering or returning to the work force as a result of welfare reform. But there have been other gains as well.

We have extended access to affordable health care coverage to an industry, and to the families working in it, which was under-served, if served at all. More importantly, the model we have developed and used so successfully with child care providers, may have applications elsewhere. It could be used to assist in recruiting other paid care givers who are in short supply, under-valued, and/or seen as "independent contractors". Personal care attendants for individuals with the most severe disabilities, as well as interpreters for the deaf and readers for the blind, are examples of potential candidates. Turnover among these service providers is also often high because of the difficult work they do, the lack of institutional supports, and inadequate wages and benefits. Offering paid or subsidized health care benefits (as well as reasonable wages) could be both a cost-effective and appropriate incentive for recruitment and retention of these hard to find and even harder to keep care providers.

Rhode Island established recently a premium assistance program, RITE Share, under Medicaid and SCHIP, which has targeted a number of the care giving industries, including long term care facilities, home health agencies, assisted living providers, and residential service providers. All of these provider groups experience high turnover rates as a result of low wages and limited health benefit packages. Through RIte Share, we hope to give workers in these industries access to the health coverage that they can not afford, but can ill-afford to do without.

Rhode Island expects its efforts in the child care arena to continue to contribute to the stabilization of the industry and to promote increases in the availability of quality child care services. To better meet this challenge, Rhode Island and its sister states would benefit considerably if afforded greater flexibility under Title XIX and Title XXI to use federal funds, or matching funds, to provide premium assistance or fully paid health coverage to care givers who are not currently eligible. Similarly, giving states the option to use Child Care Development Block Grant (CCDBG) funds to expand health care coverage to providers is both consistent with the goals of the CCDBG, and a viable strategy for reaching-out to low-income workers that might otherwise go uninsured.

Thank you again for allowing me to testify. I would be happy to answer any questions.

Written Testimony
of
Suzanne Mintz, President/Co-founder
National Family Caregivers Association
Presented to
U.S. Senate Subcommittee on Oversight of Government Management, Restructuring and the District of Columbia
On July 24, 2001
Hearing Title: Who Cares for the Caregivers?: The Role of Health Insurance in Promoting Quality Care for Seniors, Children and Individuals with Disabilities

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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 extensive 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 speak to you about the role of family caregivers in our society, the impact of being a family caregiver, and the need for family caregivers to have health insurance. Family caregivers are defined as those individuals who provide uncompensated care to a family member or friend who needs care because they are chronically ill, disabled or are elderly.

Although the term family caregiver is now understood by many, I do not believe that the role family caregivers play in society is thoroughly appreciated. Family caregivers are literally underpinning the American healthcare system.

The vast majority of care provided to chronically ill or disabled individuals is provided by family members. Approximately three-quarters of non-institutionalized adults ages 18 - 64 receive all of their care from family caregivers.[i] When we look at the 65+ population approximately two thirds of those needing care receive it solely from family.[ii] More than 50 million people provide some level of care to a loved one.[iii]

The conservative market value of services provided by family caregivers to adults was estimated in 1997 to be $196 billion dollars.[iv] And the number of family caregivers in America is growing as the population ages, as medical science continues to extend the lives of those with chronic illness, and as healthcare containment policies send people home from hospitals sooner, and in need of more care than ever before.

As former first lady Rosalynn Carter has said in her book, *"Helping Yourself Help Others"*:

> There are only four kinds of people in the world –
> those who are currently caregivers,
> those who have been caregivers,
> those who will be caregivers and those who will need caregivers.

Caregiving is often a continuum. For many it begins by providing a small amount of assistance to an aging parent or spouse with a degenerative disease and then over time becomes a 24/7 experience. For others, intensive caregiving begins very suddenly as when a baby is born severely ill, or when a loved one is in a terrible car accident or has a massive stroke.

> *I am a 35 year old mother of a 5 year old severely disabled daughter, Kaylee, who suffers from a rare genetic disorder called Camptomelic Dysplasia....Kaylee requires 24 hour medical care.*

Family caregivers provide an average of between 18 - 20 hours of care each week to loved ones 50 and older, virtually the equivalent of a half time job. Caregivers in over four million households provide at least 40 hours of care a week.[v] In a recent survey of New York City caregivers providing care to a loved one of any age, 40% were providing 20 hours of care a week or more.[vi] Over half of Alzheimer's caregivers, who are seniors themselves, provide 41 or more hours of care per week.[vii]

The surveys of family caregivers show that the number of caregiving hours has a direct correlation with the amount and type of help the care recipient requires. For instance, those helping a loved one who has a degenerative disease such as multiple sclerosis, ALS or Parkinson's, and help with a combination of several activities of daily living, such as bathing, dressing, transferring and toileting are known to provide more hours of care than those who are helping someone solely with money management, food preparation or transportation.

> *"We get up at 5 a.m. I get grandmother washed, dressed and put her in her wheelchair. While she is brushing her teeth, I get my 4-year-old and 18-month-old ready for the day. At 7:15, grandma gets on the Easter Seals bus to go to adult day care. My kids go to a babysitter, and then I work at a hospice all day. Depending on the day, I usually get home around 3:30 p.m. If I have a chance, I take a shower. If I don't, I start making dinner. Grandma gets home around 4:00. My kids get home around 4:15. We have dinner and then around 7:00 I get grandma ready for bed. Then I hit the bed...heavy... I figure that my grandmother changed my diapers when I was a kid, and now it's time for me to change hers."*

The physical and emotional impact of intensive family caregiving has been well documented.[viii] As you would imagine there is a correlation between the numbers of hours of caregiving, the extent of physical assistance provided and the actual impact of the caregiving experience. These caregivers are known to suffer more depression, and other stress related ailments than the general population. In an NFCA member survey, 61% of caregivers reported depression, 51% sleeplessness, 41% back problems.[ix] One study of elderly spousal caregivers showed that 63% of those experiencing stress had a higher mortality rate than those not stressed or in a caregiving situation.[x]

> *"I am just stressed out. I have come to a point where I am just really worried all the time. Sometimes I know I'm here, but it's hard to believe it. It seems like I'm in a dream world or something. I'm exhausted."*

The impact of caregiving is not only physical or mental. It can also be social and financial. Caregivers report feelings of isolation, a distance from "normal" life and a feeling that no one else could understand what they are going through.

> *"His condition caught us completely off guard, especially since we consider ourselves too young to have this seriously out of control health problem. I have so many newly discovered feelings: mostly, I feel a sense of tremendous loneliness and occasionally depression for the lifestyle I miss from before his illness and guilt about feeling the way I do."*

Caregiving is expensive. Families in which one person has a disability and needs help with daily living activities spend two and one half times more out of pocket on medical expenses than families without a disabled person.[xi] Thirty five percent of the general population has an income of less than $30,000. Among family caregivers that percentage rises to 43%.[xii] Caregiving literally extracts a price from caregiving families.

The majority of family caregivers are employed, nearly 64%[xiii] but over a third have reduced their work hours or taken time off because of caregiving responsibilities.[xiv] Six percent of those caring for the 50+ population have left the workforce because of their caregiver responsibilities.[xv] Forty-two percent of young parents of special needs children lack basic workplace supports, such as paid sick leave and vacation time.[xvi] Adding to the problem, family caregivers that leave the workforce, not only lose their paycheck, they lose the future benefit of the additional social security credits they would have earned.

Although I am not familiar with any studies that document how many caregivers have lost their group health insurance because they have left the workforce, anecdotal information from NFCA members suggest that for some caregivers that is the case.

> *"I had to give up both work and health insurance for a period of 6 years due to caregiving responsibilities."*
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> *"My husband's job 'disappeared' after his stroke in 1998 and with it our medical coverage."*

> *"I lost my business, health insurance and most of my savings due to the stress of caring for somebody as ill as my wife Beverly. Also I have two young children to care for and raise."*
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> *"I quit work to care for my husband and paid an exorbitant amount for COBRA insurance for both of us. When that ran out, I had to get an individual policy (which he was not eligible for) and pay for it myself."*
>
> *"I have been caregiver for my mother and aunt, both in their 80's, since 1991. I had to quit my job last year when my mother had another heart attack. I lost health, dental, vision, and disability insurance, plus pension and deferred compensation. I am presently retaining my health insurance through COBRA, but it costs me $304 per month and it will run out on 1/1/02."*

Not surprisingly, recent research on the impact that not having health insurance has on individuals and families documents that those without health insurance are twice as likely as the insured to have difficulty obtaining care for themselves and their families. For instance uninsured persons with chronic back problems (often an issue for family caregivers) are three times as likely as insured persons not to have access to a regular source of care.[xvii]

It is clear that family caregivers are making a tremendous contribution, not only to their individual loved ones, but to American society as a whole, and some of them are doing so at a huge physical, emotional and financial cost. The work that family caregivers do, the uncompensated work of caregiving that is done with feelings of love and out of a sense of duty, needs to be valued and supported in direct and meaningful ways.

Without family caregivers our current healthcare system could not function. The length of hospital stays, the need for institutionalization and professional home care services would expand significantly. Therefore, it is in the government's interest to help ensure the health of family caregivers by providing free health insurance to those caregivers who need it. If a family caregiver gets sick, or dies, who then will care for their loved one? It is less costly, more humane and better policy to protect the health of family caregivers while we can. Providing them with quality health insurance is one of the ways to do that.

Endnotes

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[v] As above, *Informal Caregiving: Compassion in Action* and National Alliance for Caregiving (NAC)/AARP, *Family Caregiving in the U.S.* 1997.

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[xi] Altman, Cooper, Cunningham, *The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Non-disabled Members*, Millbank Quarterly, 77, 1999.

[xii] As above, NFCA *Survey 2000*.

[xiii] As above, *Informal Caregiving: Compassion in Action* and *Family Caregiving in the U.S.*

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[xv] As above, *Family Caregiving in the U.S.*

[xvi] Heymann, *The Widening Gap: Why America's Working Families are in Jeopardy and What Can be Done About It*, January 2000.

[xvii] Families USA, *Getting Less Care: The Uninsured with Chronic Health Conditions*, 2001.

Testimony of
James Stearns, Esq.
Past President and Current Board Member,
United Cerebral Palsy Associations

On Health Insurance and Other Compensation for Direct-Support Attendants serving People with Disabilities

Before the
U.S. Senate Governmental Affairs Subcommittee on Oversight of Government Management, Restructuring and the District of Columbia

July 24, 2001

Good afternoon, Chairman Durbin and Members of the Subcommittee, I am James Stearns, Esq., current Board Member and Past President of the United Cerebral Palsy Associations (UCP). United Cerebral Palsy Associations was founded in 1949 by the parents of children with cerebral palsy. UCP has evolved into one of the nation's largest not-for-profit organizations serving people with disabilities through 115 affiliates in 43 states.

I appreciate this opportunity to testify on the importance of health insurance and other compensation for direct-support attendants for people with disabilities. I have the condition of cerebral palsy, have spent time in a rehabilitation facility, and was helped significantly by direct care attendants.

Direct-support attendants are also called by a variety of other job titles, and the U.S. Department of Labor uses the category "personal and home care aide." But whatever their titles, they assist people with disabilities in daily activities such as eating, dressing, and using the bathroom. These attendants are truly essential to the ability of hundreds of thousands of people with disabilities to live as independently and productively as possible.

As advocates for people with disabilities, many local UCP affiliates provide direct-support attendant services. UCP has a fifty-year history of serving people with cerebral palsy, and today two-thirds of the people we serve have other types of disabilities. But there is a national crisis with these services today because Medicaid and other third-party programs are not keeping pace with the costs necessary to provide quality attendant services. And this crisis is getting worse.

The required number of personal care attendants is expected to grow from 256,000 in 1998 to 374,000 in 2006, according to the Labor Department. This is due to demographic factors such as a rapid rise in the number of elderly persons, as well as the moral and legal imperative to support people with disabilities in the most integrated setting appropriate to their needs. States are now attempting to comply with the Supreme Court's 1999 *Olmstead* decree requiring states to provide community supports for people with disabilities where appropriate.

Even with the current demand, however, UCP affiliates are unable to recruit and retain enough personal care attendants. These affiliates report aide job vacancy rates as high as 35%, and few are accepting new clients for attendant services. This means that thousands of people with disabilities are languishing in costly government-funded institutions, and thousands more are living at home with elderly parents who are increasingly unable to take care of them. This is a shocking waste of both human capital and federal tax dollars.

Why is there an attendant shortage? Medicaid and other third-party payers usually don't cover the necessary costs of employing attendants. Private health insurance seldom covers any attendant services, while Medicaid often pays very low rates. For instance, Medicaid attendant reimbursement rates were as low as $5.24 an hour in California in

1999, $6.25 in Maine and $6.50 in Michigan, according to a study funded by the federal Department of Health and Human Services (HHS).

From such low Medicaid fees, providers must try to pay not only attendants' wages but also employer payroll taxes, and recruitment, training and liability insurance and any health insurance costs. Some providers must use charitable contributions to subsidize aide services, but this means that those providers must cut other charitable services.

In view of these low payments it is not surprising that the national average wage for personal care attendants was $7.72 in 1999, according to the Labor Department. That equates to a full-time annual income of $16,060, which was $969 below the 1999 poverty rate for a family of four.

The average wage for personal care attendants also was 87 cents an hour less than that for nursing-home aides. Although we do not have more up to date statistics, there is no indication that attendants' wages have increased.

Most attendants are highly dedicated to the people they serve, but they cannot ignore the economic reality of low compensation. Indeed, compensation is a key factor in aide turnover, according to an HHS-funded California study last year. So it's not surprising that UCP affiliates have a turnover rate of approximately 100% per year for direct support workers, and other providers have similar rates.

UCP affiliates seek to provide the best possible attendant services, but attendants' high turnover rate makes that inherently difficult. Even after extensive training, a new attendant initially will be unfamiliar with the needs of particular consumers. And high vacancy rates mean that consumers may not receive the optimal number of hours of service.

The role of these attendants is crucial to the well being of individuals with disabilities. If medications are not properly administered a person's very life may be endangered. Some of the things that an attendant needs to be trained for include, besides administering medicines, transferring and lifting, showering, dressing, feeding, catherizing, disability sensitivity, punctuality, general people skills and cooking.

I will give you just a few anecdotes from friends. One attendant mixed the peas with the applesauce because they did not seem to know any better. Another asked if he needed to turn on the stove in order to cook dinner. Another attendant, when asked to be on time, said, "find another attendant!" If the attendant does not show up on time, for many people with disabilities that means they cannot get out of bed, not even to take care of bathroom needs, and if the attendant's tardiness makes the person late for work that person's job can be put at risk.

Improper feeding methods can lead to choking and improper lifting may mean that the person with disabilities, who may already have frailties, is dropped. If the attendant hurts himself or herself through improper lifting, then the attendant can become suddenly unavailable to help their client. If an attendant is suddenly unavailable for any reason, their client's ability to get out bed, go to work and keep appointments may become impossible.

An attendant may need to drive a car, travel with their client and know what to do in emergency situations. In addition, personal security is an issue with high turnover rates. Caregivers may have a key to the home and the car, access to bank accounts and the telephone. In the worst of all cases, the caregiver relationship can create a situation where the person with disabilities is vulnerable to abuse until they are able to get to a place of safety.

High turnover rates can also mean that the person with disabilities has to constantly retrain attendants. The training period means that everything takes longer and this has a ripple effect throughout the day of the person with disabilities,

High turnover and vacancies also mean that providers must spend relatively large amounts on recruitment and training costs, thus reducing funds available for aide compensation, thereby creating a cycle of further high turnover and vacancies.

Mr. Chairman, as you have noted, many aides lack health insurance, because providers cannot afford to buy insurance or to pay wages sufficient for aides to afford the full cost of a health plan. For instance, 45% of Los Angeles County home care aides lacked health coverage last year, while 60.6% of California personal care aides statewide lacked it in 1999.

Although millions of other low-income people also are uninsured, aides' lack of health coverage has two particularly serious consequences. First, people without insurance are less likely to obtain timely medical treatment. This leads to more serious conditions and thus more time absent from work. During such absences, it is not always possible to find a substitute aide. When no aide is available, people with disabilities may be unable to eat, take medicine, or use the bathroom for many hours. And even at best, aides' absences disrupt the lives of people with disabilities.

Second, when an aide has a communicable disease, delayed treatment increases the risk of transmitting that disease to people served by the aide. Many of those people already have poor health status due to disabilities, and so are at heightened risk of further health problems and even death. That also leads to increased public program costs for treating resultant medical problems of people with disabilities.

Mr. Chairman, UCP strongly supports your draft bill to provide state formula grants to offset all or part of the cost of caregivers' health insurance. We believe enactment of your bill is one of several crucial steps that should be taken immediately to prevent the imminent collapse of community-based aide services for people with disabilities.

Funding aides' health insurance is a cost-effective approach because it would reduce Medicaid costs for aide-transmitted diseases and for recipients' medical problems caused by aide absenteeism.

UCP believes additional steps also should be taken to solve the aide crisis. We support legislation to increase Medicaid aide reimbursement rates to a specified "target" amount such as the state's average state institutional aide wage rate. Under this approach, the added cost would be 100% funded through an enhanced federal Medicaid contribution.

We also support legislation creating a federal inter-agency Task Force to develop recommendations to Congress on potential ways in which the aide shortage can be reduced. We believe options for consideration should include improved training and job retention programs, immigration policy changes, and other approaches. Finally, we support a continued annual appropriation of $50 Million for HHS "RealChoice" grants available to states to develop infrastructure to support increased use of community personal-care aides. Infrastructure projects include approaches such as multi-provider aide training consortium and an aide course-completion credential accepted by all providers in a state.

In enacting the Ticket to Work legislation in 1999 Congress rightly recognized that to be employed people with disabilities needed to have access to health insurance through a Medicaid buy in. No less the same is true in regard to those aides who many of these same individuals rely on to prepare for work each day.

If we truly value and want to enhance the independence and productivity of individuals with significant disabilities, we must find ways to value those who make such independence and productivity possible, the direct care attendant.

Thank you very much for this opportunity to address what is probably the single most urgent topic facing people with disabilities today. I would be pleased to respond to any questions or comments.

STATEMENT FOR THE RECORD OF THE AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL EMPLOYEES FOR THE U.S. SENATE SUBCOMMITTEE ON THE OVERSIGHT OF GOVERNMENT MANAGEMENT, RESTRUCTURING AND THE DISTRICT OF COLUMBIA HEARING ON THE ROLE OF HEALTH INSURANCE IN PROMOTING QUALITY CARE FOR SENIORS, CHILDREN AND INDIVIDUALS WITH DISABILITIES

July 24, 2001

The American Federation of State, County and Municipal Employees (AFSCME), AFL-CIO, appreciates the opportunity to submit this statement for the record to the Senate Subcommittee on Oversight of Government Management, Restructuring and the District of Columbia on the role of health insurance in promoting quality care for seniors, children, and individuals with disabilities. With more than 1.3 million members, AFSCME is the nation's largest public employee and health care workers union. AFSCME members provide care to the disabled, the ill, the elderly, and the very young as nurse aides, home health workers, child care workers, teachers' aides, Head Start workers, group home workers, and direct care workers in other settings.

Sadly, these caregivers often provide care in their jobs that they cannot afford for their own families. According to the U.S. Bureau of Labor Statistics, median hourly wages for health care aides range from \$7.50 to \$8.21 or \$15,590 to \$17,080 when annualized assuming full-time employment.[1] The following examples illustrate the problems that caregivers face as they do their jobs and struggle to provide for their own and their families' well-being.

> **Yolanda Sims** is an AFSCME member from Springfield, Illinois. She is a teacher's aide at the Hope School for developmentally disabled children. While Yolanda's employer does offer health insurance, she can only afford to purchase single coverage. She and her husband cannot afford the \$260 per month premium to cover their two young children, and they aren't eligible for public programs. As a result, what little health care the children do receive they get from the hospital emergency room.
>
> **Jamilla Carter** is one of New Jersey's 27,000 home health aides. She assists the elderly and disabled with eating, bathing, dressing, and personal hygiene. She cooks, cleans, and shops for them; manages their medications and takes them to their doctor's appointments; and provides companionship. She has used some of her own money to buy clients basic necessities. Jamilla makes less than \$8.50 per hour and is among the lowest paid workers in the state. She works in a job with a high risk of injury, yet she has no health insurance.

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[1] U.S. Bureau of Labor Statistics. National Occupational Employment and Wage Estimates for 1999.

An estimated 42.1 million Americans—17.4 percent of the population—were uninsured in 1999 and this number continues to grow. The lack of health insurance is primarily a problem of the working poor, not the unemployed. Over eight in ten uninsured Americans are workers or dependents of workers,[2] and most of these are in families with incomes below 200 percent of the federal poverty level.

A survey that Home Health Care 1199/AFSCME conducted this year of home health aides in northern New Jersey highlights this problem among caregivers. Almost 70 percent of the home health aides interviewed were uninsured. Of those who were insured, only 18 percent were covered through a family member's health plan. For those who were eligible for employer-sponsored health insurance, premiums averaged over ten percent of their income, and therefore affordability was a real issue.

Turnover rates among low wage caregivers are extremely high. As a result, they cycle in and out of employment that may or may not offer health insurance. Continuity of health care coverage does impact positively on health status. In January 2001, the Commonwealth Fund released a report[3] in which they compared access to care of the insured, the uninsured and those with a recent time uninsured. The researchers found that, compared to the continuously insured, those insured but with a recent time uninsured were at high risk of going without needed care and of having problems paying medical bills. This group was two to three times as likely as those with continuos coverage to report access problems. The study concluded that focusing on current insurance status alone will underestimate the extent to which having a time uninsured during the year contributes to access difficulties and undermines quality of care.

AFSCME believes that the impact of being uninsured must, at some point, make it more difficult for caregivers to provide quality care to clients for the following reasons:

- **Missed workdays because of avoidable health problems** — According to a report by the GAO the uninsured are likely to forego many health maintenance services such as check-ups and preventive services. As a result they can require acute, costly medical attention for conditions that may be preventable with early detection and/or treatment. Studies have found that the uninsured are hospitalized at least 50 percent more often than the insured for avoidable hospital conditions.[4]

- **Working while injured or sick** — Unaccounted for is the number of workers who continue to work while sick or injured. Many injuries go unreported unless they are severe. Low wage hourly workers cannot afford to take a day to rest a tired back or other painful condition, nor can they easily afford a visit to the doctor's office. As a result, efficiency and effectiveness are diminished. The job may get done, but not as well.

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[2] "The Uninsured: Kaiser Public Opinion Update." Kaiser Family Foundation, April 2000.

[3] "Role of Insurance in Promoting Access to Care - Uninsured and Unstably Insured: The Importance of Continuous Insurance Coverage." The Commonwealth Fund; January 2001.

[4] "Health Insurance: Characteristics and Trends in the Uninsured Population." Testimony before the Committee on Finance, U.S. Senate; GAO; March 13, 2001

- **Working under stress** — The availability of health insurance provides financial security against potential catastrophic costs associated with medical care. For workers who have chronic health conditions or who worry about the health of their family members, the anxiety produced by financial concerns can prove to be a significant distraction from the responsibilities of providing care.

AFSCME Is Working to Help Uninsured Direct Care Workers.

The caregiver staffing crisis, particularly among low wage health care workers, is expected to worsen as baby boomers age and the need for services increases. It is imperative that we develop strategies for attracting and retaining people to do these jobs. AFSCME has approached this from several angles:

- At the state level, AFSCME has worked to increase the Medicaid reimbursement rates to providers, with these increases targeted to improving wages and health insurance. We have worked in coalition with other groups, and in some cases employers, on successful "wage pass-through" campaigns in New Jersey, Illinois, California, and Wisconsin.

- We are advocates for the expansion and increased funding at the state and federal levels for public programs such as SCHIP, Head Start, child care and Medicaid.

- We have been and continue to be involved in living wage campaigns in cities across the country, such as Baltimore, Minneapolis, and New York.

- Some AFSCME Councils have developed training and upgrading funds that provide low wage workers with job training. These programs have enabled workers to improve their job skills in their current positions and to prepare them advance into other, better paying positions.

AFSCME Supports the Caregivers Access to Health Insurance Act of 2001.

AFSCME has a long history of supporting quality, affordable health care for all and for this reason strongly supports the Caregivers Access to Health Insurance Act of 2001. The Act addresses the crisis of uninsured caregivers and their families by assisting states to expand coverage and by providing incentives to attract and retain quality caregivers.

The bill sets up a program that would be modeled after the State Children's Health Insurance Program (SCHIP), with an enhanced federal matching rate and fixed allotments for states. States would have flexibility in deciding how to provide the coverage. AFSCME particularly supports the provisions that require the coordination with other health insurance programs and the enrollment of those who are eligible into the State Medicaid program.

Public employees who are fulfilling these caregiver roles must be eligible for health care coverage under this bill, unlike their current exclusion under the SCHIP program. AFSCME supports the ability for buy-in to the state employee health plan, but this raises difficult ERISA issues because of the mixing of public and private employees.

AFSCME is committed to working with the subcommittee on this bill to ensure that caregivers and their families get affordable health insurance coverage. They and the clients they serve deserve no less.

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TESTIMONY

BEFORE THE

COMMITTEE ON GOVERNMENTAL AFFAIRS

SUBCOMMITTEE ON OVERSIGHT OF GOVERNMENT MANAGEMENT, RESTRUCTURING AND THE DISTRICT OF COLUMBIA

UNITED STATES SENATE

THE HONORABLE RICHARD J. DURBIN, CHAIRMAN

JULY 24, 2001

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WHO CARES FOR THE CAREGIVERS?: THE ROLE OF HEALTH INSURANCE IN PROMOTING QUALITY CARE FOR SENIORS, CHILDREN AND INDIVIDUALS WITH DISABILITIES

The National Association for Home Care (NAHC), the nation's largest organization representing home care and hospice providers and the patients they serve, extends its thanks to you for your efforts to explore how health insurance for caregivers can be a tool to promote quality care in programs serving children, seniors and people living with disabilities. We look forward to working with you and other members of Congress to address this vital issue.

Securing and retaining sufficient staff to meet our nation's growing caregiving needs has become one of the greatest challenges facing home care providers today. Expanding the availability of health insurance for caregivers and their families is a key ingredient to recruitment and retention of this vital workforce.

Senator Durbin, we believe that you, in particular, are to be commended for your vision and understanding of the importance of providing health insurance to these important caregivers. While the need for health insurance among all low-income workers is crucial, ensuring the availability of these vital benefits to low-wage caregivers is particularly compelling and would have far-reaching, positive effects, including:

- Ensuring a healthier caregiver workforce;
- Increasing incentives to enter and stay in this important field;
- Reducing absenteeism;
- Minimizing lost productivity of family members who, absent the availability of formal caregivers, must reduce work hours or quit working entirely to care for aging or ailing relatives;
- Preventing the spread of contagious illness; and
- Relieving health conditions that might, if unattended, contribute to the incidence of workplace injuries. This is particularly important, as home care agencies are currently experiencing increasing difficulty securing workers compensation insurance.

LACK OF HEALTH INSURANCE FOR HOME CARE AIDES

In its May 2001 testimony before the Senate Committee on Health, Education, Labor and Pensions, the U.S. General Accounting Office found that aides working in home care and nursing homes are much more likely than other workers to be uninsured and living below the poverty line. According to their data, 32.1% of home health aides lacked health insurance as compared with 16.4% of all workers.

An Institute of Medicine study on "Improving the Quality of Long Term Care" (2001) found that the low rates built into Medicare and Medicaid reimbursement are particularly important reasons for the low wages and benefits in long term care. Moreover, wages and benefits for home care and home health workers were found to be significantly lower than for those in acute care settings.

REPORTS FROM THE STATES

A study by the California HealthCare Foundation, published in February 2000, found that 45% of the nearly 72,000 home care workers in Los Angeles County were uninsured. Ninety percent of the uninsured home care workers were found to be living below or near the poverty level. Over 40% of uninsured home care workers delayed or did not receive needed medical care because they could not afford it. This rate was five times higher compared to those home care workers who did have insurance. Low pay and lack of benefits, the report concluded, forces these caregivers to have second and third jobs or to continually look for better jobs. High turnover in these caregiving jobs acts as a disincentive for employers to provide employee training. The net result may be that some of our seniors and people with disabilities are attended by inexperienced, untrained, and even exhausted caregivers, if they can find care at all.

The Massachusetts Home and Health Care Association conducted a survey of 17 home care agencies in Massachusetts, all of which offered health insurance to employees who worked 20 or more hours a week. Twenty-eight percent of home health aides worked less than 20 hours a week and most of these part time workers were not offered health insurance. The survey found that the average health insurance premium contribution required of employees was 40%, which can be prohibitive for low-wage workers. Forty-one percent of the aides who worked more than 20 hours a week chose not to participate, most likely because of the large premium contribution required. Every agency reported significant premium increases over the past year. In their narrative comments several agencies attributed their higher-than-normal premium increases to the composition of their work force, women age 40 or above. Almost all agencies expressed a desire to be able to pay more toward insurance as an important retention and recruitment tool.

The executive director of the Connecticut Association for Home Care reports that there is a health care access problem in home care as a result of staffing shortages that limit resources to the point of having to refuse admissions. The executive director of the Home Health Assembly of New Jersey reports that New Jersey is going through the worst shortage of home health nurses and aides in her 30 years experience in home care. New Jersey reports a dramatic decline in the number of new home health aides becoming certified. Recently, hospital discharge planners from her state, as well as New York, called her association to ask what they could do when no Medicare home health agency in a patient's county had sufficient staff to accept new referrals.

The executive director of the Associated Home Health Industries of Florida reports that provider members are having to turn down thousands of hours of personal care requests because of the lack of paraprofessional staff. He predicts the home care worker shortage will be the number one issue for home care over the next five years.

The Kansas Home Care Association reports turnover rates as high as 50% for home care aides who provide visits of two or four hours minimum.

THE DIRECT CARE STAFFING SHORTAGE IN HOME CARE

The home care industry has a history of periodic difficulties in recruiting and retaining qualified nurses, home care aides, and other direct care workers. However, in recent years, numerous factors have had the combined effect of transforming these cyclical difficulties into a crisis situation. Among these are: dramatic reductions in reimbursement for home health agencies resulting from the Balanced Budget Act of 1997 (BBA); a flood of new and costly regulatory requirements; low unemployment rates; the competitive disadvantage home care agencies have over employers that are able to offer higher wages, better benefits, and more attractive work schedules; an aging population and increasing longevity; the continuing trend on the part of hospitals to release patients quicker and sicker; technological developments that allow more complex treatments to be performed in the home; and the preference of most consumers to remain in their homes as long as possible.

In contrast with other providers, such as hospitals and skilled nursing facilities, the staff-to-patient ratio in home care is **at a minimum** one staff member per patient. Further, home health providers have been discouraged by the Medicare program from using telehomecare devices and other technological advances that might allow for more efficient use of staff. These factors help to exacerbate the problem of meeting staffing needs.

Faced with a severe shortage of nurses and aides, agencies cannot provide services to many patients. Indicative of this trend is the fact that patients served by the Medicare home health benefit dropped by nearly 1 million between 1997 and 1999 and claims dropped nearly 50%. While the Medicare home health program has moved to a prospective payment system (PPS), the harmful effects of the BBA cuts continue to limit agencies' ability to provide adequate wages and benefits, because the global budget set for this first year of PPS restricts outlays to what would have been spent if the previous payment system had continued. For this reason, there is a great likelihood that episode payment rates under PPS may be inadequate, thereby perpetuating staffing shortages and access problems for patients.

Staffing levels of home health agencies have decreased dramatically. From 1996 to 2000, over 173,000 full-time positions in Medicare-certified agencies were lost. This reduction in full-time equivalent (FTE) staffing includes 65,034 fewer nurses and 72,366 fewer home health aides available to care for patients in 2000 than were employed by agencies in 1996 (HCFA, Online Survey and Certification Reporting System, 1/1/2001 and 12/31/97, respectively).

The Homecare Salary and Benefits Report (2000-2001), published by the Hospital and Healthcare Compensation Service and the National Association for Home Care, found annual turnover rates of 21.01% for registered nurses, 23.69% for licensed practical nurses, and 27.79% for home care aides. Based on direct information from home care agencies throughout the nation, these figures appear to be low in comparison with what agencies are actually experiencing (see NAHC Survey below).

The Bureau of Labor Statistics reported that the median wage for home health aides in 1999 (the latest data available) was $8.36 an hour; for home care aides, $6.90.

In an editorial, the *New York Times* recognized the growing shortage of paraprofessional health aides (February 4, 2000). "The shortage of workers willing to bathe, dress, feed, clean, and care for the elderly in their homes and in nursing homes," the editorial said, "has grown worse in the last two years as the economy has continued to soar, creating many other jobs that pay as well or better for much less demanding work. Fast-food restaurants and Target stores now may offer equal wages, steadier work and better benefits, and zookeepers, toll-takers and manicurists actually earn more." The *Times* concluded that their wages and benefits are held at such low levels in part because of cuts in Medicare, which pays for some home health care.

PENNSYLVANIA STUDY ON PARAPROFESSIONAL DIRECT CARE SHORTAGE: IMPLICATIONS FOR THE NATION

A comprehensive study of the long-term-care paraprofessional workforce was recently completed for the Pennsylvania Intra-Governmental Council on Long Term Care. The report, entitled "Pennsylvania's Frontline Workers in Long Term Care: The Provider Organization Perspective" (Polisher Research Institute at the Philadelphia Geriatric Center, February 2001), is part of a broad initiative to understand the extent of the problem of recruitment and retention of paraprofessional direct care workers, and to gather information that can lead to strategies to address this rapidly growing problem in Pennsylvania and throughout the nation.

The study found that the paraprofessional shortage is limiting the amount of long term care that the industry can provide and is having a negative effect on quality of care. Furthermore, the high turnover rates place a considerable financial burden on providers due to high recruitment and training costs.

The problem is widespread. A survey of state administrators cited in the report showed that 42 out of the 48 responding states consider the recruitment and retention of frontline paraprofessional long term care workers a major workforce issue. The study found that the forces underlying the shortages are not likely to disappear even if the growth of the economy slows and unemployment rates rise.

Over 71% of home health and home care agencies reported shortages, with 18% reporting them to be severe. More than 26% of home health and home care agencies had job vacancy rates exceeding 20%. Nearly 70% of providers reported significant problems with either recruitment or retention and 35% reported that the problems were extreme. Most reported that the problems have worsened over the last two years. Forty-five percent of the certified home health agencies reported serious recruitment problems; 17% reported serious retention problems.

The data showed that staff shortages reduced access, particularly among home health and home care agencies. Forty-six percent of home care agencies reported service cutbacks. The report concluded that, "Since home care is the fastest growing segment of the long term care industry both for the nation as well as for Pennsylvania, and the type of service most preferred by consumers, such cutbacks demand attention and must command a response."

Home health agencies that offered health insurance, particularly to part time workers, less frequently reported recruitment and retention problems. Providers that made additional contributions toward premiums for employees who elect family health coverage reported significantly less retention problems. This points up an additional dimension of the health insurance problem for caregivers -- the lack of health insurance for their families.

NAHC NATIONAL SURVEY OF STAFF SHORTAGES

With respect to hiring difficulties in home care agencies, a recent NAHC membership survey found that 69% are having difficulty attracting home care aides and 60% report difficulty retaining home care aides (NAHC, February 2001). NAHC conducted a survey in March 2001 of 209 provider agencies representing all 10 Health Care Financing Administration (HCFA) regions. All agency categories were represented; however, the "not for profit" response was disproportionately large (56.5 %). Preliminary survey analysis confirms there is a severe shortage of home care aides with 48.4% reporting unfilled home care aide positions. In addition, 33.7% report they have had to refuse patient admissions due to insufficient staff. Sixty-one percent of agencies in Region II (NY, NJ) report they have had to refuse patient admissions. This is a significant indicator of access to care problems for consumers in certain geographic areas.

The overall turnover rate was reported to be 39.1%. The vacancy rate is 10.9%. Certain regions of the country are having greater recruitment and retention difficulties. For example, 76.9% of the agencies in Region II report unfilled positions followed by Region VII (Iowa, Kansas, Missouri, and Nebraska) with 66.7%.

Lack of health insurance was cited as one of the reasons home care aides leave their positions. Providing health insurance was ranked as one of the top four methods for retaining home care aides.

INCREASED DEMAND FOR DIRECT CARE WORKERS

The employment concerns provided in this testimony stand in sharp contrast to forecasts of continued growth in demand for home care personnel. In late 1999, the Bureau of Labor Statistics forecast for the period 1998-2008 an increase of 21.7% in the demand for registered nurses and a 19.7% increase in demand for licensed practical and vocational nurses. A severe shortage of personal care and home health aides is also expected -- demand for these workers is expected to grow by 58.1%. Home care staff of the future will have to be highly skilled and specialized, with sophisticated computer knowledge and the ability to use technology, such as telemedicine.

The US Bureau of the Census predicts the population age 85 and older will double between 1994 and 2025, from 3.5 million to 7 million, and to nearly quadruple by 2040. The Urban Institute predicts that persons with two or more limitations in activities of daily living (ADLs) will increase from 4 million in 1990 to nearly 6 million in 2010, and 9 million in 2030. Successful recruitment and retention of caregivers is vital if our nation hopes to help individuals maintain maximum functioning and remain in the least restrictive living environment.

RECOMMENDATIONS TO EXPAND HEALTH INSURANCE FOR CAREGIVERS

NAHC recommends that this committee support the following measures to expand access to health insurance for caregivers and their families:

1) Provide a federal subsidy for health insurance for caregivers.

In their January 2001 report on direct care health workers, the Paraprofessional Healthcare Institute reported that the state of Rhode Island guaranteed health insurance for all in-home child care providers by expanding its Medicaid insurance program--an initiative that could be replicated for health care workers. New York passed the Health Care Reform Act that in part increased access to health care benefits for home care workers.

The federal government should take action to encourage and support such efforts on the part of the states to provide caregiver health insurance by subsidizing the provision of health insurance for caregivers. Consideration should be given to creating a national health insurance program, such as through an expansion of the Medicaid program, for all direct care workers, funded all or in part with federal dollars.

In January 2000 the Commonwealth Fund's Task Force on the Future of Health Insurance for Working Americans presented a survey that found that although most Americans believe that employers are the best source of health coverage, nearly all of those surveyed were in favor of the government helping low-income working families pay for insurance.

2) Adjust Reimbursements to Allow for the Provision of Health Insurance

Congress should provide that Medicare, Medicaid and other federal programs that finance home care and hospice services adjust reimbursement to allow for appropriate benefit levels for all clinical staff. Essential first steps should include eliminating the additional 15% cut in Medicare home health reimbursement scheduled for October 1, 2002, as proposed by Senator Susan Collins (R-ME) and others (S.326); restoring the full market basket updates for home health and hospice; and permanently extending the 10% add-on to the PPS base payment for patients in rural areas. Congress should level the playing field by requiring that the same wage index and geographic reclassifications used to establish Medicare inpatient hospital payments be used in determining payments to home health agencies.

3) Request GAO and MedPAC studies

Congress should request General Accounting Office and Medicare Payment Advisory Commission (MedPAC) studies on the lack of health insurance for caregivers in home care and hospice settings, with special attention to rural and inner-city areas, and with recommendations on what can be done to overcome this problem.

4) Reduce Regulatory Burdens and Costs

Increased Congressional oversight of HCFA's regulatory authority to ensure public input in rule-making and decreased regulatory burdens would greatly reduce costs, freeing more resources for the provision of health insurance for caregivers. The Medicare Education and Regulatory Reform Act (MERFA), S. 452, introduced by Senators Frank Murkowski (R-AK) and John Kerry (D-MA), and "The Home Health Nurse and Patient Act" (S. 1169), introduced by Senators Russ Feingold (D-WI), Frank Murkowski (R-AK), John Kerry (D-MA), and Susan Collins (R-ME), are two of a number of bills that would help address this issue.

Mr. Chairman and members of the Committee, thank you again for holding a hearing on health insurance for caregivers. We look forward to working with you to address this important issue.

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TESTIMONY of Mardell Bell
Service Employees International Union
Local 880, Illinois
Before the U.S. Senate Committee on Government Affairs
Subcommittee on Oversight of Government Management,
Restructuring and the District of Columbia

July 24, 2001

RE: Health Care for Home Care and other Long-term Care Workers

My name is Mardell Bell, I am a home care worker and a member of Service Employees International Union (SEIU) Local 880 in Illinois. I live in Dolton, a suburb of Chicago and have worked for four years as a home care aide.

On behalf of my fellow home care members of Local 880 and SEIU, I thank you for this opportunity to testify before the Subcommittee. We especially appreciate Senator Durbin's interest in the issue of health care for home care workers and his efforts to address the problem of uninsured caregivers.

SEIU represents 185,000 home care workers throughout the U.S. and Canada, including 13,000 in Illinois. Our membership includes individuals working as independent providers in publicly funded programs and those who are employees of home care agencies who are providing both publicly and privately paid services. Home care workers provide essential services to people with disabilities of all ages by assisting with basic personal care needs. Home care aides are the people who bathe, feed, dress and care for the nation's ever-growing number of people with disabilities who are living in the community. Without home care aides, there would be no home care.

What we home care workers have in common is a dedication to our clients and a strong desire to make home care a quality job. We work as home care aides in spite of low wages and a lack of benefits, including health care insurance. Less than half of all home care workers receive employer-sponsored health benefits. With an average wage of only $7.50 per hour, few workers can afford to purchase individual coverage, and family coverage is well beyond their means. A significant percentage of workers with families are eligible for public assistance and Medicaid coverage.

I have been without health insurance for the four years I've been a home care worker. For most of those years I never went to the doctor. Without health insurance you don't have anywhere to go and if you go to the county you have to wait all night to be seen. On home care wages we need every penny we can get. I have three daughters and my husband's job closed down so I am the only bread winner right now. So I was just a trouper when I would get sick. I knew I had to take care of my family so I just kept going. But in December the sickness and asthma overtook me and I couldn't keep going.

I was diagnosed with severe asthma, bronchitis and sinus problems. I have had numerous tests to understand what is wrong and they want me to take more tests to understand if my illnesses has caused heart damage.

I go to the county hospital and I pay the lowest rate but I still have $1,200 in bills, and they say I need a lot of additional tests. With the medication I feel good, I can do my work. My client has 16 steps going up to the bedroom and 12 steps to the basement and I am running up and down the stairs all day long. Still I need to start finding a way to pay for the tests. My credit is ruined.

It is rough when you don't have insurance. I go to the emergency room at night so I don't have to miss work. But I have to wait at least 10 hours to be seen. It takes 2 months to get an appointment at a clinic. My next appointment is scheduled for September 7th. It takes 7 days to get a prescription filled. So when I run out I just pray I don't have an asthma attack. My doctor says if you have any problems just go to the nearest emergency room, but that will mean another big bill. In home care we need every hour of work we can get and we don't get sick days or vacation. It doesn't work to use a public health system that makes you wait so much.

There is no replacement staff so if we don't show up our clients go without care. Last week I had an appointment to get a test taken but my client also had an appointment for a test at the same time. So I canceled my appointment, because my client can decide at anytime that I am not reliable and fire me. I can't risk getting fired by not being there. There are only a few hours that you are allowed to pick up you medication. It is always when I am at work. Fortunately I have been able to come in a little late and work late to make it up but it all takes a lot of negotiating and it is frustrating to those that are dependent on our care.

I just have routine chronic health problems that can be controlled with medicine, but I am still deeply in debt and worried about my future health care as a result of high medical bills. But I know a lot of home care workers with far greater problems than me and no help.

A recent General Accounting Office study on the shortage of nurse aides included an analysis of health insurance and other benefits. One-third of home health aides lacked public or private health insurance coverage, compared to 16 percent of all workers in the U.S. Studies in California and Illinois documented an even higher rate of uninsured among home care workers.

Among our membership at SEIU Local 880's in Illinois, 58 percent of home care workers under age 65 are uninsured. The typical Illinois home care worker is female; middle-aged; African American; has a high school education; works full-time; is a single head of her household; earns less than $7.00 per hour; is interested in pursuing additional health care training and lacks health insurance. The survey of SEIU Local 880 members from which this profile is derived also found that in the past year, 41.3 percent of home care workers had to choose between buying food and paying their medical bills.

An additional finding from this Illinois study is that part-time workers were more likely to have health insurance than full-time workers. Typically, part-time workers have a family member or a second job that provides health insurance benefits or they are eligible for public medical assistance. Another reason to provide job-based health insurance to home care workers is it will allow some portion of the current part-time workforce to be available for full-time work. The current "shortage" of home care aides would be somewhat alleviated and would reduce dependence on public benefits.

In Illinois, we are working hard to create a health fund for home care workers funded through a combination of state and federal funds. Working with community organizations we have held rallies and held events to bring attention to the problems faced by uninsured home care workers. We have also worked with employers to provide data on the uninsured home care population in Illinois. While we were successful in passing legislation out of the House, we have not yet won our battle.

An extensive study of home care workers in Los Angeles published in 1999 by researchers at the University of Southern California found that 45 percent of LA home care workers were uninsured and 80 percent live in a household that has income below 200 percent of the Federal Poverty Level. In general, home care workers in LA are predominantly women (83 percent); older (more than half over age 45); racially and ethnically diverse (39 percent Latina, 25 percent African American, 14 percent Armenian and Russian decent); and poor or near poor (80 percent live in a household with income below 200 percent of Federal Poverty Level). The survey identified significant hardships endured by uninsured home care workers, many who delay care and have chronic medical conditions that go untreated.

In March, the LA Board of Supervisors voted to begin providing health insurance to 74,000 IHSS workers in the county. Los Angeles joins 6 other counties in California that are committed to or already providing health insurance to home care workers. These are the same counties that have established public authorities for home care services.

There is an extreme waste of public resources when workers are uninsured. Turnover rates that exceed 100 percent in some programs, and difficulties recruiting new staff to the home care field can be linked to the lack of basic benefits available to home care aides. Workers leave the field because they cannot afford to stay. Constant training and recruitment costs drain money that could more appropriately be used to improve wages and benefits that would keep workers on the job and improve the quality of care. Although the personal care and home care aide job is the seventh fastest growing job in the nation, the 850,000 persons currently working in the field are without basic benefits. Unless something is done to address this problem, the gap between those who need personal care services and those who are available to provide services in the community will grow. The care will simply not be there.

The problem of access to health insurance extends to nursing home workers. SEIU surveyed certified nurse aides (CNAs) in 1998 and found 22 percent were uninsured, compared to 14.5 percent of the total workforce in that year. This survey was conducted during a period of prosperity in the nursing home industry, yet even when coverage was offered to workers, only 50 percent of CNAs chose to participate in their employers' plans because of the high cost. Only 44 percent had family coverage, compared to 60 percent of workers in all industries in 1998.

Improvements in workforce retention and the accompanying continuity of care occur when home care aides have employer-based health insurance. The San Francisco public authority, which has raised wages and provides health insurance to its members has begun to make strides in improving retention rates. SEIU's 9,000 members in the San Francisco In-Home Supportive Services (IHSS) program receive comprehensive, affordable health coverage, including dental benefits. These benefits were negotiated through contracts with the San Francisco public authority, a county-based agency that oversees the program and serves as the employer of record.

Barriers to coverage for these low-wage workers are related to job conditions. Part-time work is typical in home care. As a result, home care aides may be excluded from benefits offered to full-time staff in an agency due to insufficient hours worked. Instead of viewing this as an insurmountable barrier, policymakers should look to solutions that encourage full-time positions while allowing part-time workers to have access to health benefits. For example, home care workers in seven California counties have been able to negotiate comprehensive, affordable health insurance coverage for workers who work a less than full-time schedule and these may include family members providing services to IHSS recipients.

I once ran a small business, so I know it is difficult to purchase affordable employee benefits. Participation in joint labor-management Taft-Hartley health benefit funds helps to alleviate this barrier by grouping employers together into much larger pools that can negotiate improved rates from insurers. SEIU home care workers in New York created a comprehensive health benefit for home care workers. We see this as an excellent model we would like to replicate across the country.

What can the government do about the lack of comprehensive, affordable health insurance? Calling attention to the problem is the first step. Hearings such as this one bring attention to the issue. Solutions are available.

As the steward of public programs that provide the majority of home care services to the nation's eligible populations, government reimbursement for services at the federal, state and municipal levels should be adequate to provide a living wage and basic benefits, including health care for home care workers. When states contract with private employers to provide services, contractors must be held accountable for their use of public funds, particularly when the government's intention is to carry out the public's desire to fix a problem in the workforce such as inadequate pay and benefits. SEIU home care workers in California, Illinois, New York and Arkansas have been able to negotiate improvements in wage and benefits by working in coalition with consumer groups to improve reimbursement rates for publicly funded services with the explicit intention of improving the quality of the workforce. But we are far from the quality job we are aiming to create.

Finally, government should develop, encourage and replicate demonstration projects that provide comprehensive, affordable coverage to home care workers. As an example, there is a demonstration program in New York with SEIU 1199 that created a managed care plan that bridges Medicaid and Taft-Hartley funded programs allowing Medicaid- and COBRA-eligible workers who lose their eligibility for the union-funded plan because their hours dropped below the minimum to maintain the same source of care.

In sum, there needs to be a joint effort between government, labor and employers to find solutions to barriers to health insurance for home care workers. SEIU pledges its help in working to provide health benefits for home care and other direct care workers in the health care field who are unfairly and unnecessarily denied access to a benefit offered to the majority of employed people in the United States.

SEIU, the Service Employees International Union, is the largest home care union in the U.S. representing 185,000 home care and 120,000 nursing home employees nationwide. With 1.4 million members—including 710,000 in health care—SEIU is America's largest health care union and the largest union in the AFL-CIO.