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Judy Waxman

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YOUR MOTHER'S MEDICINE: A NEW APPROACH TO THE HEALTH CARE OF WOMEN THROUGHOUT THEIR LIFESPAN

Judy Waxman*:

I was part of the health care reform effort in the early 1990s with the Clinton Administration. We made some serious progress, but in the end there were many reasons why the effort failed. We will be facing some of the same issues today, but there also seems to be a feeling, at least among a lot of the people who were involved before, that this is the time there is a greater sense of urgency. The timing presents a golden opportunity.

There are a lot of reasons why we need health reform. Forty-six million Americans do not have health insurance. Costs are increasing astronomically and health care is becoming a larger and larger part of our Gross Domestic Product. Costs are increasing at a pace where if we do not figure out how to cover everybody and control costs at some point in the not so distant future, 100 percent of our Gross Domestic Product may be health care.

The National Women's Law Center is involved in a variety of issues that affect women. I am head of the Health and Reproductive Rights Group. For the last thirty-five years, we have done a lot of work on health care and display lots of information on our website, expanding the scope of what National Women's Law Center does. We issue a federal and state report card on "Making the Grade on Women's Health," which goes state by state looking at statistics on how women are actually faring. It is based on many different indicators, including what policies at a federal and state level might help women have better health.

Looking at health reform specifically, you might also notice that we have a special project on health reform and women. I will go into a little bit of detail on a few issues that women face. Health care for all and controlling costs for all will obviously help women.

* Ms. Judy Waxman is the Vice President, Director of Health and Reproductive Rights at the National Women's Law Center (NWLC). The NWLC works to promote the quality and availability of health care, including reproductive rights choices for American women through advocacy, policy, and education strategies. Ms. Waxman served as Deputy Executive Director at Families USA for over a decade and has also been an adjunct professor at the Georgetown University Law Center and an attorney at the National Health Law Program in the Department of Health and Human Services.

When we look a little more closely, we see that women have some special needs separate and apart from men. Affordability is one of them. The individual insurance market is detrimental to women. I will cover that and the general questions we should be asking about health reform.

First of all, let us take a look at insurance coverage patterns. More women have coverage than men at the moment. The real reason is that women have less income than men overall, and so Medicaid and other low income programs cover more women than men. In private insurance, the pattern is somewhat different. While men and women have private coverage at about the same percentages, more women than men are covered as dependents, which can affect their coverage. Furthermore, when you look at women by race, you can see that insurance coverage varies dramatically in terms of who actually has coverage. That, of course, is linked very much to poverty and levels of income.

If we are going to build on our current employer-based insurance system, then we have to figure out how to deal with part-time female workers. Building on the employer system is possibly a good way to go, but we must deal with it as a women's issue. It is true that women in the affordability gap generally use more services than men, due to their reproductive health needs and other issues. Obviously, it is not any individual man versus any individual woman, but across the board women tend to receive more health care. There is a large affordability gap, which is evidenced by family out-of-pocket costs and premiums; women wind up spending a whole lot more out of their pocket than men do. Women have more cost related access barriers and are less likely to take the medication prescribed to them. Women have more medical debt, which is one of the major causes of bankruptcy in this country.

Where do women get their health care coverage right now? Eighteen to sixty-four year olds get their coverage mostly from employer sponsored coverage. Seven percent are covered under the individual market. That is the group where, for example, you graduate law



school, you do not have a job yet, and your parents say you must have health insurance. You go online and you try to find out what plans are available. It is a brutal market because each individual is looked at separately. You are not in a big group where your medical costs are combined with everybody else's, sharing the risk, which is the whole point of insurance. It is pretty wide open in terms of what companies can do and what they can look at about you, whether they approve you or not, what you are charged, and so forth. We looked at this issue in terms of men versus women.

As I said, women generally use more services than men. However, we decided to do a study to see how women were charged in the individual market. We looked at plans in two states, which had similar criteria, so we were comparing apples to apples. What we found at ages twenty-five, forty, and fifty-five was that there were gigantic differences around the country in what women versus men were actually being charged. At age twenty-five women were being charged between six and forty-five percent more; at forty, between four and forty-eight percent more. Then, at fifty-five in some instances it switched and men were actually charged more. The numbers were all over the place and totally arbitrary. Should there be a difference? Should we all be in this together because any individual is not necessarily representative of the whole group? For example, in this country we do not rate by race. No matter what your race is, no matter if one race has certain problems that would cause medical expenses to be incurred and another race does not, we do not look race in insurance. We do not say, "we are going to charge you more because you're X."

We started to wonder with this vast variation between men and women, whether we should be charging by gender in this country at all. Of course, when we show these numbers to people, they always say "well, that is because of maternity care." What I want to tell you is, no it is not, because the plans that we picked expressly did not cover maternity care. It turns out that in the individual market, maternity care is mostly not covered. Only twelve percent of plans nationwide have comprehensive maternity coverage. Nine percent have something that they call maternity coverage, but it is more like, "we will give you \$2000 towards whatever your expenses are." Twenty percent offer a supplemental maternity rider, meaning you buy the plan and if you want the maternity coverage you have to pay extra. Of course, you could not get it if you were already pregnant and some of them even have waiting periods. For example, you may have to wait six months to get pregnant after you start the plan.

There are additional challenges in the individual market. I wanted to mention that there are still nine states and DC in which insurers can reject applicants because they are survivors of domestic violence. The insurance company figures that they do not want to cover a person who may be victimized again and have medical expenses. We have also been hearing that once a woman has a Caesarian section, a company may not want her because she may have another one. She may never have children again, but they still do not want to take that chance. Obviously, ratings based on age, your general health status, and any pre-existing condition poses challenges in the individual market.

The reason I bring up all of these issues in terms of the individual market is because there are a lot of health care reform proposals that build on the individual market. Both former President Bush's and Senator McCain's plan proposed giving people tax credits to buy individual health insurance.

I hope that some of the evidence I just laid out for you explains why the National Women's Law Center thinks that that is not in the best interest of consumers. We believe that there should be some kind of plan where as many of us as possible are basketed together because that is the point of insurance. Rather than each of us buying an individual plan and the company deciding what they want to cover, the company goes out and purchases a group plan.

I want to end with eight questions we should consider going forward. Will everybody be covered? Will the plan provide care that is affordable? Will there be comprehensive benefits? Does the plan adopt insurance market reforms to end unfair practices? Does the plan preserve or expand the role of public health insurance, as well as the employer sponsored health plan? Will disparities be addressed? Lastly, will the plan control costs while ensuring quality? Those are very big prescriptions we need to look out for, but we can do it.

Suzanne Mintz*:

There is not a family in the country that is not going to have some level of caregiving experience in the future. That is because people are living longer. Medical science has found ways to keep people alive longer, despite the fact that they have serious conditions. The nature of our society is such that the people who need the most care now are from the World War II generation. Boomers have fewer kids than the World War II generation had boomers. There are going to be fewer people around in twenty or thirty years to provide care for another family member or friend, which obviously raises issues of how care is going to be given to persons with chronic illnesses and disabilities in the country.

That gets to some of the issues that Judy Waxman was talking about: the need to improve quality and control costs. I want to ask you one other question before I get going. Has anybody heard of the term 'coordination' and 'continuity of care'? That is an issue you are going to hear a lot about in health care reform because the lack of it is one of the major drivers of increased costs. There have been a number of programs that show that when there is continuity and coordination of care, we actually reduce costs.

It has what I call 'the passability factor,' which is something that is going to be critical in all of the discussions. If reform does not save money, it most likely is not going to happen. The question put out by the program was "Does SexX Really Matter? What a difference an X makes!" I want to give you a brief background on the National Family Caregivers' Association (NFCA). We are the leading organization of and for family caregivers in the

* Suzanne Mintz is the President and Co-founder of The National Family Caregivers Association (NFCA). She took her personal experience with her husband's diagnosis of MS and its impact on their lives, and built a national organization to improve the lives of family caregivers. The National Family Caregivers Association has empowered hundreds of thousands of individual family caregivers to take their own lives and speak on behalf of themselves and their loved ones. In addition to her work with health care professionals, public policy makers and the media, she has transformed the lens through which we view family caregiving and helped to raise it from being considered solely a personal experience, to being one of the most important health care issues of our time. She is also a member of the Board of the National Health Council, the Board of Governors of the National Patient Safety Foundation, the Advisory Board of the Partnership to Fight Chronic Disease, and the Advisory Task of the National Transition for Care Coalition.

country. We reach across the life span and individual diagnoses to address the common needs and concerns of all family caregivers. Our mission is to empower family caregivers to act on behalf of themselves and their loved ones and to remove barriers to health and well-being. That is what I call a bottom-up and a top-down approach. You have to give people information and a sense of confidence in order for them to feel that they have a role to play and that their voices will be heard. Top-down obviously deals with the issues of health reform and bringing about systemic changes to our system.

I want to give you a short primer on family caregiving today. There are more than fifty million people in the country, who provide care to a loved-one who is chronically ill or disabled. That is about twenty percent of the population. The market value of these services is \$375 billion per year that is provided for free. That could never be duplicated by the system. So, family caregivers are literally underpinning all of long-term care in the country. A typical family caregiver is a forty-six year old married woman, who works while also caring for her mother, but does not live with her. There are people who give a minimum amount of help. They may just be starting out, helping Mom with the groceries or taking over paying her bills. Then there are the people, of course, who are providing around-the-clock care for someone who has multiple chronic conditions, such as a soldier who has returned from Iraq and is disabled.

Family caregiving has become a huge issue for the business community because it causes businesses to lose between seventeen and thirty-four billion dollars every year. This is calculated in terms of lost productivity. For example, people making phone calls to find out how to get services while they are at work. They come in late and leave early. Then there is something called 'presenteeism' when you are there, but you are not there. All of those factors go into businesses choosing to help their family caregiving employees because it is easier to keep them and have them be productive. Initially, companies started providing things called INR, Information and Referral Services. It was not getting a whole lot of pickup and was not changing a lot. Some large employers are offering some very innovative programs, such as paying for immediate homecare if someone's homecare aid cannot come. Companies are offering flex time and using virtual communications to help people balance their home and work life issues.

I want to talk about the unmet needs of family caregivers. There is the lack of recognition and respect from the health care community, as well as from payors, that family caregivers have much higher rates of depression, chronic illness, and premature aging. Judy Waxman talked about women having higher rates of chronic illness, depression, and other mental problems. There is a correlation here. In a study done to find out about the impacts of stress researchers looked at parents of children with special needs for their study population. Specifically the study included women who had children with Down Syndrome, Cerebral Palsy, or mental retardation. They looked at young women because if you are trying to measure premature aging, it is a lot harder for those of us who have already aged. What they have found is that there is a slowing of or lack of growth in telomeres in the tips of fingers. These have to do with the renewal of neurons and other things that keep us younger. They found that under extreme stress, family caregivers can age as many as 10 years. The study was duplicated by a researcher looking at older caregivers and caregivers of people with Alzheimer's disease. This

is extraordinarily stressful because you are dealing with a combination of physical and mental stress, making caregiving harder.

Another unmet need is that family caregivers are health care workers who receive absolutely no training. We do not get any education, we do not get peer support, and we certainly do not get paid or get vacation. If you think of family caregivers as part of the work force, which the Institute of Medicine did for its study on the work force around aging society, why would you hire us? Why would you want to hire somebody who is overly emotionally involved with the patient? There are reasons that surgeons do not operate on their own family members. Again, we are not trained for this job, we just popped into it. Fifty-nine percent of family caregivers are in the workforce. They are isolated from the other people who are doing the same jobs. If you look at it from that perspective, you realize that family caregivers have a whole lot of unmet needs and by extension so does the system that is using our services.

Caregiving is expensive. Caregiving families tend to have lower incomes than average, but have much higher out-of-pocket expenses than the average population. You get people who are being squeezed at both ends of the spectrum. We get more calls at NSCA for people trying to find out if there is any financial assistance for caregiving families. Unfortunately, we have to say no. Some states have some emergency funding for caregiving, but most do not. In Medicaid, there is a program called Cash and Counseling, which allows people to be their own managers in terms of getting services. In traditional Medicaid, people are given a plan of care and it is prescribed and provided by companies or services in the community. Under Cash and Counseling, they become their own boss, so money is literally given to the Medicaid recipient and they can go out and use the money to buy the services that they think they need. It is called Cash and Counseling because there is a counselor to assist with all of this. Under that program, in certain states, people have begun to pay the family member or friend doing the caregiving from their Cash and Counseling allowance.

I talked somewhat about the costs at business and some of the programs that are coming down the pike. Pitney Bowes is always mentioned as a company that has put together a really good program. Most big companies are putting together something these days. Certainly an unmet need of family caregivers is political power. We are an invisible population and because family caregivers are all doing their jobs separately, there is no cohesiveness or self-identity. If you ask someone if they are a family caregiver, they might say no. But, if you ask them if they are caring for somebody with a chronic illness or disability, they would say yes. People recognize the tasks they do, but they do not recognize the nomenclature. They do not recognize the label of family caregiving. I think that is for several reasons. So many people think this is just what you do for a family member, which of course is true, but we have twenty-first century medicine today and the care that is being requested is totally different. More people used to die of infectious and then penicillin and other medications came along allowing people to outlive infection. Now people live longer and get things like Alzheimer's or Parkinson's. People are surprised when I mention that the average age of death in 1900 was forty-seven. Today, the average age is around seventy-seven. If a person cared for a family-member in 1900, it was always for a short duration. Now, caregiving goes on for years. It can go on for fifteen or twenty years for someone with Alzheimer's. My

husband has Multiple Sclerosis, which is a disease of young adults. He was thirty-one when he was diagnosed. He is sixty-five now; do the math. We have been dealing with some aspect of having a chronic illness for over thirty years.

It is important for family caregivers to get political power, but it is very difficult to have them come together as a large force for change. One reason is that they do not see this as a political issue. Again, it is what you do. We got a quote from one woman in a focus group some years back that I have never forgotten. She said something to the effect of, "well, it sounds like you're turning this into a political issue. It's not, it's a personal issue. You're taking all the love out of it." My response was "no, it is because we love that we want to make things better." We really do have a shot with health care reform right now, which is extremely exciting. If you cannot get a huge group of family caregivers to come to Washington, you can bring their stories, which are extremely compelling.

I want to get to the essential question: does sex matter? These days in family caregiving, the answer is not so much. It used to be a seventy-five to twenty-five split: seventy-five percent of caregivers were women, twenty-five percent male. Now it is sixty-forty. Both are likely to be primary family caregivers, meaning the main person doing everything. Both equally provide help with what are called "instrumental activities of daily living," which has to do with grocery shopping, managing medications, and driving to the doctor. More women than men provide hands-on help such as helping someone get in and out of bed, helping them shower, and helping them use the toilet. Those, of course, are the activities that create more stress, which is what creates the situation in which family caregivers are more prone to chronic illness, depression, and premature aging. More men than women do long-distance caregiving. You live here, mom and dad live in Florida. You see a lot of people dealing with long distance. They are on the phone a lot and they will go down more often than they might have before. They might try to convince Mom that she should wear some sort of a buzzer system or, in some cases, install a monitoring device so that you can know if Mom gets out of bed at the regular time. The more technology, the more opportunities there are for monitoring people from a distance. That allows people to stay in their homes longer.

Both men and women caregivers report taking time off from work, adjusting their schedules, considering a job change, and refusing jobs that require a lot of travel. Both report not being aware of the benefits that they have at work. Even though companies are putting benefits in place, a lot of people are not taking advantage of them. More women talk about caregiving when they are at work. Men tend to keep quiet. There is always fear at work whether I should tell my boss.

Picking up on health care reform, there are opportunities for change. America has what we call an acute care system. If you are in a car accident, you're taken to the E.R. The people we are dealing with that cost Medicare, Medicaid, and private insurers the most money are those with chronic conditions. Changing the system to provide better chronic illness care that is coordinated and continuous across settings holds a great deal of promise for improving quality, lowering costs to the systems, and taking stress off family caregivers and their loved ones. I think it is essential that we support the critical role of family caregivers by providing some education, training, support, and, for those who need it, financial assistance. Those are small things compared to everything that family caregivers do. It will minimize errors and save enormous amounts of money. That is where NFCA is focusing its energies in terms of health care reform. There are many opportunities for students when you get out in the world in terms of being a lawyer dealing with health care. You can work for companies that provide health insurance. You can work in the field of tort reform, in terms of minimizing the number of suits and getting fairer equity in the system. People who have been affected by a medical error want more than anything else to make sure that nobody else is affected in the same way. They want financial equity. If someone's husband has died and he was the main breadwinner, there are certainly costs. If a child has become disabled because of a medical error, there are costs involved. You can always work on the Hill and focus on health care issues there. There are millions of opportunities for you. I hope that you will consider health care law as a really good opportunity for you down the road.