

## SAGE CROSSROADS

**PERRY:** It's a great pleasure to be here in Seattle tonight, and to welcome you to this forum. One of the things that brings us here is a relationship between the Alliance for Aging Research and the Women's Bioethics Project based here in Seattle, which was founded by Kathryn Hinsch, whom I will be introducing in a moment. She will then tee off our panel discussion, and lead our exploration tonight.

A program of the Alliance for Aging Research over last several years has been to bring the issues of bioethics and the social impact of an aging population closer to thought leaders, to policy makers, and to you, the American public.

For nearly twenty years, the Alliance for Aging Research has been a force in your nation's capital, making sure that funding is flowing for the National Institutes of Health, and that national policies are appropriately preparing us for the unique experience of a larger, older population than we've ever experienced.

In a matter of months you will probably be reading in newspapers and seeing on television that now the average life expectancy for a baby girl born in the United States will be eighty years, at birth. This crosses an important threshold. What it signals in its own way is that we will be experiencing longer lives for women and for men, but there is a six-year differential of women living longer than men on average, and thus experiencing life at later ages in a way that men do not.

And that's, in part, what we will be exploring tonight.

But let me say a word about SAGE Crossroads. This is a program of the Alliance for Aging Research in conjunction with the American Association for the Advancement of Science. You may know this organization as the publisher of the highly regarded *Science* magazine. SAGE Crossroads looks at what will be the social impact, the legal impact, the ethical impact, the political impact as we experience longer and longer lives—we hope at higher degrees of health and function and vitality than any generation has known before.

Our scientists tell us that this is going to happen. This generation of American women who have helped redefine gender roles, who have given new dimensions and new meaning to childbirth and to family development, are now going to be the first to experience longer, healthier and more vital life at older ages.

We are beginning this discussion through SAGE Crossroads, and particularly tonight, in partnership with the Women's Bioethics Project, to really plumb what that will mean.

SAGE Crossroads is monthly webcast at this site—and I want everyone to either mentally record this or jot it down—it's [www.sagecrossroads.net](http://www.sagecrossroads.net). SAGE is an acronym for the "science of aging," and we are looking at the crossroads of how advances in science and medicine will interact with our personal lives, our community lives, and affect us all across our society.

Tonight's event, in which you will hear from these distinguished panelists and from Kathryn Hinsch herself will be available on [www.sagecrossroads.net](http://www.sagecrossroads.net) on June 21. And while you're there, you may go back and look at over thirty live events—webcast events such as this, debates, interviews with leaders in the field of the science of aging, panel discussions—that are exploring the many facets of aging and health. I invite you to look at that.

Now, without taking up any more of your time, I want to get to this exciting panel. We will have questions from the audience and it will all be followed by a reception.

But let me introduce Kathryn Hinsch. She's the founder of the Women's Bioethics Project, based in Seattle. This is an extraordinary network of women leaders in your community who are helping plumb the women's perspective on not only aging, but on health and biotechnology. She's done amazing work to create a powerful, influential and well-networked organization in scarcely more than a year. Tonight really inaugurates what I believe will be the first of many interactions between the national Alliance for Aging Research and the Women's Bioethics Project.

So, again, I welcome you; and I would like to recognize and thank Kathryn Hinsch of the Women's Bioethics Project. Kathryn.

*[Applause]*

**HINSCH:** Thanks. Thank you. I, too, would like to add my welcome to our Women and Aging: Ethical Implications Panel today. I would like to thank Dan Perry and his staff at the Alliance for Aging Research, and SAGE Crossroads for partnering with the Women's Bioethics Project. And I want to thank all of you for being here tonight. I know on a summer day in Seattle, although it doesn't seem very summery out, that there are all sorts of alternatives where you could be. The fact that you are here with us tonight means a great deal.

I wanted to tell you a little bit about the Women's Bioethics Project. We are a think tank, a public policy institute, nonpartisan, as Dan said, based here in Seattle. Our mission in life is to make sure on a variety of bioethical issues that women's voices, life experience and health are represented.

We focus on neuro-ethics, women's health, and reproductive technologies.

Founded less than a year ago, we've been able to do some incredible things, working together. We have a distinguished board of directors, of which many are here this evening. We have testified before the FDA on the new breast implants. We have given a keynote speech—actually, I gave the keynote speech—at the UN Bioethics Center and it was pretty incredible. It was certainly a different experience than this evening as I now look out and see all these wonderful women here. I'm so glad to have you with us.

We have a fully functional website. I invite you all to take a look at that as we update the content. We've put on numerous successful events. I hope this will fall in that category.

Last week I was part of a panel that the Women's Bioethics Project presented at the Seattle Rotary, Downtown Rotary, also a very different group than this evening. It was on the ethical implications of stem cell research. While we do think it's very important that we weigh in on these very politically contentious issues, we also believe that it's important to think about ethical issues that really impact the reality of women's life. Issues of women and aging and ethics, we feel, are as important, perhaps even more important, to our lives.

We'd also like to thank those of you who responded to our email survey. We were very interested in your responses, and the issues that you talked about—about what it means to grow old, the ageism that many of you have experienced. My heart broke as women talked about feeling invisible, devalued, about the housing needs, about the financial burdens, about what it means to go through menopause. These were an incredible list of topics. I am afraid we are only going to touch on a few of them tonight; but I want you to know that we heard you, we've put them into our program analysis, and we will be, I hope, doing future forums.

As we explore the topic of women and aging, of course we are not talking about women as a homogeneous group. Each of us has different burdens and opportunities, experiences, and life views. Race, class, sexual orientation, of course, all play an important part in focusing our reality of aging. To some, the very notion that there would be different ethical implications for and about women is an absurd notion. But once examined, and I think we will demonstrate this evening, there are profound differences that need to be addressed.

Today our panel scholars are from the field of law, medicine, humanities and social work. They will look at the assumptions, experiences, practices and public policies that affect women's wellbeing, self respect, and dignity as we age.

Please allow me to briefly introduce our scholars. You will find more detailed biographical information on each of them in each of your packets.

Dr. Nancy Hooyman. She is dean emeritus at the University of Washington School of Social Work. Dr. Hooyman is also the co-director of the School's new Institute for Multi-Generational Health Development and Equality, and the recipient of the school's first endowed professorship in gerontology.

Dr. Patricia Kuszler. Associate Dean of the University of Washington's School of Law, professor in the departments of Medical History, Ethics and Health Services. An attorney as well as a physician, Dr. Kuszler is an internationally recognized leader in bioethics, health care and the law.

Dr. Helene Starks, assistant professor, the Department of Medical History and Ethics at the University of Washington School of Medicine. Dr. Starks' research interests include issues related to end of life for patients, their families, clinicians and health systems. Her special interests include feminist and narrative approaches to bioethics.

And, Dr. Artee Young, professor at the Evergreen State College, my alma mater! She currently teaches at the Tacoma campus and, over the past 25 years, she has designed and taught courses in law, public policy, theater, literature, as well as bioethics. Since 1989, Dr. Young has practiced law, and for two years was a judicial clerk for two justices of the Washington State Supreme Court.

Here is how today's panel is going to work. We've given each scholar a broad topic to address on "Women, Aging and Ethical Implications." They will each have five minutes—and I've given them all their own clocks so we can keep a time on this—and in those five minutes we've asked them to cover key topic areas, policy shaping the issues, and ethical implications.

Following their remarks, we will then open it up for a group panel, where we will delve in more deeply to one particular ethical issue. Following the group discussion, we will then open it up to the audience.

I am going to ask you then to go to the microphone. We are recording this, and so we will need you to line up at the Q&A time, and I will cue you on that.

At the end of the Q&A, we will go back to the scholars and ask them for one policy recommendation that we as a think tank need to work on to move forward, because we're not just about talking about these issues, but we're about action and making life better for women.

Immediately following the panel discussion, Q&A, we will then go off to the room to the side continue our conversation. Because we believe this really is a conversation between the panel and those of you in the room, so we can make life better.

We've asked Dr. Kuszler to speak on women, aging, and the health care system. Dr. Kuszler?

**KUSZLER:** Well, thank you Kathryn. It's an honor to speak to you all today, and especially to be on such a distinguished panel. I apologize that I have a bit of laryngitis so I hope you will be able to hear me.

I have a very nice narrow topic, which was—early in our discussions was phrased as "access, finance and justice." So I will not be able to cover all of these things, but I hope to give you a little bit of a flavor of some of the issues that confront us as we look at health care, not only domestically here in the United States, but internationally as a society of women caring for other women.

The focus in the United States—I would say one of our biggest problems is that our health care system is not very coherent. Indeed, it would be—I would phrase it as somewhat schizoid.

*[Laughter]*

We have an unusual arrangement compared to other countries in the sense that our health care for our non-elderly population is dominated by the private health care coverage approach, whereby we purchase, or our employer purchases, health care coverage for us from private companies, sometimes referred loosely to as insurers, but basically health plans.

On the flip side, however, health care for the elderly is dominated by Medicare, a very large public entitlement plan that provides at variable levels for hospital care, physician care, prescription drug coverage. This public entitlement plan really was set up during the 1960s during the Great Society of Lyndon Johnson, to really provide a safety net for the elderly that would be present for the elderly regardless of whether they were rich or they were poor.

Well, this unfortunate sort of bi-modal approach we have with a private system on one side and a public entitlement system that kicks in at age sixty-five, has led to some serious financial problems.

First of all, the way the entire system functions is that the current generation covers the cost of the previous generation that is aging. So, as we take a look at the federal program struggling today, it is because, of course, as we put money in a generation ago, it is not the same amount of money that that particular generation takes out today. So we have a constant sort of playing of catch-up.

Health care gets more expensive and more money goes out of the system. Meanwhile, there are fewer and fewer people—fewer workers per retiree putting money into the system. This, when placed in the context of demographics, produces, and will continue to produce, some serious difficulties.

First of all, let me touch on some of the demographics, which I think all of the other panelists will speak to as well. Older women are likely to survive longer. This is a very good thing!

*[Laughter]*

However, this has complications because women, if they marry, tend to marry men who are slightly older and, as a result, as women get older, they are more frequently going to be alone, even if they chose to be married during their lives.

The net result is among people—women over 85 percent—of people over eighty-five years and older, 50 percent of the men are still married. Only 13 percent of the women

are. So you can see immediately that we have some difficulties here. That leads to a greater likelihood of living alone for women. Nearly 30 percent of Medicare beneficiaries live alone. Of these, 72 percent are women.

So you can see already we have a constant skewing toward women living to be older, living longer, and living alone.

Many elderly persons have diminished resources, and, indeed, typically, as seniors get older—the average eighty-five-year-old person's income tends to be much, much lower than it was during their life—their normal life—their earlier life span.

There is an increased unlikelihood of informal caregivers. This is a worldwide phenomenon. Even though the elderly are comparatively wealthier than earlier generations, we still have a situation where Medicare does not cover most of health care costs—only about half. So people become increasingly impoverished over time, as they spend for their health care costs, and more importantly, as they care for their spouse who likely ate up all of the disposable income and health care resources, and then they have fifteen or twenty years of relative good health, but relative poverty to live in.

I am getting the high sign here that my time is almost up. I do want to tell you that as we look at our ethical burden as women in trying to better our societal situation for health care, we are trying to better it not just for women, but for the generation that will become behind us—as well as from an international perspective. We have similar problems that other nations have in terms of women being imperiled as they grow older in terms of becoming lifelong caretakers, lifetime caregivers, and doing so with ever fewer resources.

**HINSCH:** Thank you very much, Dr. Kuszler. Sobering statistics. One of the women who e-mailed us her survey information said one of the things that was really difficult and she didn't expect as growing older, is that she would miss the company of men. So one of our scholars suggested that perhaps we start a movement of dating younger men! But that is a topic for a whole 'nother panel.

*[Laughter]*

So moving forward, Dr. Hooyman, we have asked her to talk about, briefly, the issue of women and lifelong care-giving.

**HOOYMAN:** Thank you. I am going to be addressing the ethics of care-giving across the life span, and probably every one of you here in this room has been or will be a caregiver. But you may not have thought about the fact that societal expectations that you will assume the care-giving role are really a feminist, moral and ethical issue.

Care-giving work is the most important work in our society, but it is devalued and least rewarded. The term care-giving is often used as if it were gender-neutral. That overlooks the fact that the reality is that women provide 80 percent of in-home care to older adults. Women are primary caregivers, whether we think of it in terms of unpaid family

caregivers, underpaid direct care workers, the chore workers, nurse's aids, personal assistants who provide the important hands-on care in long-term care settings. Women are predominate among the paid caregivers that work with older adults, whether social workers, nurses, geriatric physicians, and so on.

This gendered nature of care across the life span is a structural issue. Our long-term care system is based on the assumption that women and a few men provide the majority of care for elders, yet policymakers, along with families, take women's care-giving for granted.

Family caregivers save our government about \$196 million a year; but, as you probably all know, the supports that are available to family caregivers don't begin to match that amount.

Our society's emphasis on "private," which means family responsibility, is unfair and has negative consequences for women in old age, as reflected in lower retirement benefits and higher rates of poverty.

Martha Holstein, a philosopher who has written about the ethics of care, states, "Women who do this care role are subordinate, devalued and hailed as saints, none of which does much to pay the bills or deepen self respect."

*[Laughter]*

Given the growth of older adults and the projected shortages of all three types of caregivers in the future, our society is headed for a crisis of care. I want to briefly make a few more points about the three different types of caregivers, and some of the ethical issues.

First, the unpaid caregivers of children, elders and grandchildren. Again, we can see women predominating, whether it's caring for young adults with disabilities, caring for spouses in old age, caring for parents or parents-in-law or grandparents in middle age—that's the group that's often referred to as women in the middle, or the sandwich generation, because they face demands from the older generation, often from younger generation, and that whole phenomena of the boomerang kids who've left home and they come back again. So that when you think you are going to have an empty nest, it fills up again.

Women are much more likely to be employed than in the past. So a lot of responsibilities are getting stacked on top of that.

A relatively recently identified phenomena is the tremendous growth of women as primary caregivers of grandchildren or great-grandchildren. In effect, the sandwich generation has now become a club sandwich, because we have some women who are responsible for four generations—their parents, their grandchildren, and their adult children who are largely absent or invisible.

This is an area that raises tremendous ethical issues in terms of the legal, financial and instructional barriers that grandmothers face in trying to provide care.

Next, the underpaid caregivers who really provide the majority of hands-on care in long-term care facilities. These are often low-income young women, often immigrant women, women of color, who are caring for low-income women in old age. We all know the statistics about how poorly direct-care workers are paid, and how little respect is given them for their very essential role.

Then, again, thinking about the paid caregivers who serve older adults, we are facing real challenges of recruitment and retention across a variety of health-care disciplines and we'll be facing a major short fall, shortage of health-care workers for the boomers when they become the senior boomers.

We can come back and talk about how these three areas of care-giving interconnect, but the bottom line—it's a profound ethical and moral issue that affects every aspect of women's lives, and is the least valued work in our society.

**HINSCH:** Thank you, Dr. Hooyman. That was fabulous. Often on the panels on aging, often it's looked at from a medical perspective or from a legal perspective, or from a social work perspective. We felt it was important—in fact, we feel it's important from the Women's Bioethics Project think tank perspective—that we always include the humanities perspective. So we have asked Dr. Young to speak about issues of aging and power and class and race. All of these ethical issues have to be taken in consideration and framed and looked in these broader contexts. Dr. Young?

**YOUNG:** Thank you very much.

I'm going to address mainly two issues: gender differences in status and power as people age; and secondly, the impact of class and race on women's aging experiences. Largely I'm focusing on women of color. Ralph Ellison wrote a book a long time ago called, *Invisible Man*, but if you look at issues of health and bioethics, you begin to see that there is in fact an invisible woman of color.

So I want to in some way bring their issues and concerns to you tonight.

Cultural constructions of later life differ among racial and ethnic groups. Almost 35 million citizens of the United States, one in eight, are aged sixty-five or older. Three out of five are women. Of these, one of every six older woman is either African American, Hispanic, Native American, or Asian American Pacific Islander.

By the year 2030, one in four older Americans, irrespective of gender, will be a person of color. As the United States grows more diverse, the elder population is also becoming more racially and ethnically complex. The effects of aging are compounded by the additional effects of race, class and gender.

If we look at social, economic and political power, we have an idea of the impact of aging on these women of color as they grow older. In looking at social power, I am looking at two determinants: education and quality of health care.

Social power. There's considerable evidence to demonstrate that an individual's educational status is an important predictor of mortality and morbidity. Educational trends, inequality trends, are exacerbated as persons grow older. Lack of an education places women at higher risk for health and social problems.

There's a term—"quadruple jeopardy"—referring to the simultaneous effects of being old, a minority, female, and poor. In 2050, women of color will represent 25 percent of the population; and those data are probably inaccurate, because if you are not aware, most people of color don't report. The census is quite inaccurate when it comes to reporting on data related to persons of color. Imagine the numbers of new immigrants in the country who are not reported. So I think these numbers are a little low based on the reality of my experiences and my knowledge.

Educational attainment is associated with skills and social benefits, which come with increasing educational levels. Skills may include the ability to process certain kinds of information or critical thinking and the ability to interact with bureaucracies, institutions, and health practitioners.

Social benefits of this power may include credentials and the economic access they provide, social networks and cultural capital, socializing to adopt health-promoting behaviors and enhanced expectations for the future, leading to planning self-efficacy and a sense of control.

The relative importance of these effects may be period- and cohort-specific, and most often are affected deeply by race, ethnicity, and gender.

The economic return for a given level of education varies importantly by race and gender. It may also vary by the prestige of the institution that one has attended. There's an example of the Delaney sisters—Sadie and Bessie Delaney—two African American women who are now deceased. They lived well into their nineties and over one hundred, and they were some feisty old ladies. They wrote a book called *Having Our Say*. In the book their personal accounts of their pasts and then current lives, as well-educated, professional women, spanning history from reconstruction to the Harlem renaissance, up to the 1990s. Their stories show how the advantage of being high up in the hierarchy of social class intersects with the disadvantage of being low in the hierarchies of race and gender.

There's another component I want to mention and that's geographic location. Women in rural communities, poor women, women of color in remote areas, have limited access to health care. Compounding this is data showing that African Americans, particularly coming from the northeastern states, are moving to the South, returning home, where

there's a shortage of doctors. They're going into those rural areas that they left to go into the cities to find work and have a life beyond segregation.

Now that they're older and retired, they're returning home. I think there are lots of problems associated with that great nostalgia, but they're going to a place they haven't lived in forty, fifty, sixty years. I think they are going to encounter some difficulties.

The other issue I want to raise very quickly here in terms of social power and economic power is the notion of women of color who don't get basic health care. Whether they're just sloppy and they don't want to get it or whether their incomes don't allow for them to have access to certain kinds of health care is another issue.

For instance, the U.S. Preventive Services Task Force recommends a single dose of pneumococcal vaccine for adults sixty-five years of age and over. It provides protection against consequence of pneumonia. Among adults sixty-five years and older, only 39 percent of African Americans get the vaccine, 42 percent of Hispanics or Latino adults—compared to 64 percent of white adults.

Likewise with influenza vaccinations. Only 48 percent of African American blacks get the vaccine. Fifty-five percent of Hispanic or Latino adults compared to 67 percent of whites who receive the flu vaccine.

Even more alarming for me, only 27 percent of Asian Pacific Islander women, 27.1 percent of African American women, 33 percent of Hispanic women, and 40.1 percent of Alaskan Native American women over age forty have received a mammogram in the past two years.

A staggering 73 percent of American Indian women have not even had a blood pressure screening.

There is a lot of work to be done. Access to primary care is an increasing concern of aging women of color, and this disparity must be addressed and remedied.

With respect to economic power, factors of age, sex, race, ethnicity, marital status, living arrangements, educational attainment, former occupation, work history, are characteristics associated with significant economic differences. Elderly women have higher rates of poverty. Poverty rates among blacks—33 percent, 22 percent of Hispanics. These are women.

Low socio-economic status is correlated with increased health problems and other common problems of aging, such as arthritis, orthopedic impairments, hypertension, etc.

I won't go into the wage gap because I am sure that you have heard a lot about it. But retirement is a moving target. More women are continuing to work past the standard age, retirement age, particularly women of color. For those that are retired, this means that

they started to collect Social Security at age sixty-two, sixty-five, at a time when the amount is lowered.

In order to address issues associated with women of color, it's also important to respect differences in cultures. In the United States we look at what a person look like. "Oh, you look like you're African American. Oh, you look like you're Native American." So we have a very superficial kind of knowledge of people and we make hasty assessments about them.

With the ever-increasing population of people of color, it's important that we become culturally literate and competent. New immigrant populations have different cultures, yet we tend to group them with categories of people: African Americans, Native Americans, Hispanics. Yet, there's a more specific kind of culture operating among these women.

For an example, if we look at a case of a Filipino family that I know, there is a son who is married, a daughter who is married and a daughter who's never been married. And she's the mother's caretaker.

She has a "duty" as part of her culture to care for her mother and that duty outweighs her duty to herself. She, herself, is becoming incapacitated, is sleeping on the floor, so that her mother doesn't have to walk up the stairs. So she is sleeping with her there, on the floor, so that she can attend to her every need. This is not an issue that she feels as if she has some control over. She has no control. It is her culture that is mandating this kind of behavior. This love for her mother is exemplified through her care for her.

We have all of these kinds of things. I don't know about my time—one minute! I'm very conscious of it. Because I wanted to talk about caregivers, women of color, Chinese immigrant women, African American women, who are caring for children with disabilities.

In most communities of color, mental health diseases are embarrassments to the family, so they are often hidden. These women—saints, to borrow a term uttered down the way here—saints they are—they are literally killing themselves as they attempt to care for people with schizophrenia, other kinds of mental health diseases, and at the same time, keep it away from the rest of the community—the community is not to know about this—and interfamilial conflict over who should be doing what.

So we find women of color really, truly, between the proverbial rock and a hard place.

It is my expectation and my hope that when these kinds of panels are assembled and when you do your research and teach your classes, that you will remember women of color because they are, in fact, the invisible women in our society. Thank you.

**HINSCH:** Thank you, Dr. Young. It certainly brought me back to those wonderful Evergreen lectures, and I wondered—I would not even consider interrupting my professor! So I thank you so much for that impassioned, lovely speech.

We're also going to hear tonight from Dr. Helene Starks, and she has actually been an amazing mentor to me in helping the Bioethics Project think broadly about bioethical issues. She's also been coaching us on how to manage scholars. It's harder than you might think!

*[Laughter]*

Dr. Starks will conclude our overview section, by looking at the issue of planning for death versus planning for decline. Dr. Starks.

**STARKS:** Thank you. I want to just build a little bit on what everyone else has said, and I would like to talk about this in the context of how women live out the end of their lives. I'll be talking about this in terms of how we construct community, and what it will take to support feminist and feminine long-term care.

I think for many of us it's a lot easier in some ways to think about what we would or would not want at the very end of our lives, at death. We've had debates like the Terri Schiavo case recently, where we've realized that we have to make some tough decisions about the very end of our lives, and how we might think about our dying.

I think it's a lot harder for us to think about what the last five to fifteen years of our life might look like. The last thing we want to do is plan for our decline. You know, we can almost think about what life is like at the very end, but getting there is a path that we don't really want to relish.

I think the good news is that part of our longer life span includes a healthier life, and there's a concept of compression of morbidity, which means that we probably won't be so sick for so long. But still, there's all that uncertainty. We're not quite sure what those last years are going to look like.

Given some of the statistics that my colleagues have presented, though, I think it's likely to be realistic and think that we are going to be single, maybe widowed or divorced. We'll be living alone. We won't have a lot of money. We'll probably have some health care needs of our own. That's sort of going to be our reality.

But there's another reality that I think is equally important, and that is geographic mobility. Artee mentioned it a little bit about folks moving home. That's something that older adults are going to be doing more and more of, in part because our families have become quite dispersed. Our families—that word “family” has really changed. That doesn't mean what it used to mean.

We have multiple, mixed families. We have ex-daughter-in-laws who are taking care of their former mothers-in-law because they liked them. They didn't like their sons, but they liked their mothers-in-law. So they are still caring for them.

We've got kids of all kinds of different families that have affiliations that come together and come apart. Biology means a whole lot less to us than it did before. And biology is also an issue because we're all having smaller families.

In the good old days, a big huge family is where you knew you had a bunch of kids and that was a good thing because they'd take care of you when you were old. And that meant forty-five.

Now, we have much smaller families and we are living much longer. As Nancy said, we are not only the sandwich generation, we're the club sandwich. We are asking women to do more care-giving with fewer resources all around—less time, less money, less social support, more love to spread around to more folks who need their attention.

So we think about what's going to happen to us when we get older. What happens is that there often is some kind of a health crisis or widowhood or you lose a spouse and you find yourself in a place where you are going to need to move. And a move often means to some other part of the country, and most of us don't want to think about that because we stay in our homes for a reason. Our home is where we are who we are. It's a place where we develop our identity. We develop that identity through our friends, through our colleagues, through our bingo, through our churches, and when we have to move, we leave all that behind. It sounds like, "Oh, well, I'm going to move across the country to be close to my kids." But then, can your kids provide all the things that your community gave you?

One of the things that I don't think we're really thinking about—and especially this is true for women, because women are the ones who are going to be moving—is where are we moving to? Where is it, exactly, that we want to go or can we go? So if we are moving home, and home isn't ready for us, what does that mean?

Not only that, if we are moving because our care needs are increasing, who's going to provide that care for us? We are stressing our kids out by asking them to care for us. We actually don't want to ask that of them. We want to help them. We don't want to make ourselves a burden on them.

So what's going on?

Well, actually there are some ideas about building communities of care, and I know there are a lot of people in the audience tonight who feel passionately about that. I want you to find me afterward because I want to talk to you about this idea. The idea of the community of care is a place where they—it's not an institution. It's alternatives to nursing home care—that we don't want to have places where we are warehoused. We want places where we continue to be who we are, where we can connect, have meaningful lives, productive lives, creative lives, loving lives.

Some of those places are things like continuing care communities. There are some good examples here in Seattle. Small adult family homes, where you get to adopt a family or a

family will adopt you. Adult residential care facilities where—they are an interesting kind of club in a funny way. Different assisted living facilities. We have special dementia care facilities now that are much more humane places for people with dementia to continue to be who they are as much as they can be, as well as traditional nursing homes.

There are some other interesting options that might—that are growing on a smaller scale, such as co-housing projects. I personally am in a group of women where we have recognized, because a lot of us don't have any kids, that we are going to be "it" for each other. So we are starting now in our forties, and we are building a community because we know that our friends are going to be the ones to take care of us. We don't have kids to rely on us, or for us to rely on.

The issue about how we are going to fund this is not even on the table. Long-term care right now is really expensive. Average nursing home care is about \$35,000 a year, although Liz Taylor tells us that in the Seattle area it is more like \$72,000 a year. That this is one of the most expensive long-term care markets in the country.

I don't know how many of you have \$72,000 in your pocket, but I don't. I don't think any of us do, and we are not even thinking about it. This is not only a problem because of that horrendous number on each one of us, but think of this: there are going to be about 10 million older adults by the year 2030, so that is going to be about \$350 billion a year paying for long-term care, which is currently mostly paid for by Medicaid and by you. Two thirds of the cost of long-term care is covered either by—set aside for the poor or out-of-pocket expenses. Medicare only pays a quarter, and currently private long-term care pays about 4 percent of the overall cost.

We are not prepared for this landslide at all.

Here's what I think we need to do—some ethical issues here are how are we going to pay for this, how are we going to restructure our society so we can create affordable long-term care that can be provided in supportive communities, where we can continue to grow and foster our identities?

I will leave it there.

**HINSCH:** Excellent. Thank you very much to all of our scholars for the overview.

We are currently in discussions with SAGE Crossroads about taking this panel and doing it at a national level, and I think I am going to need to insist that we get three days rather than an hour and fifteen minutes.

But that said, we are going to move into our group panel discussion; I'm going to throw out a question, crossfire-like at them, for them to address, and then I'm going to shorten that time a little bit to make sure we don't lose the time that we have for hearing from all of you.

So dear scholars, care-giving has always fallen to women. How is the reality of women's lives different today? What are some of the ethical considerations we should be addressing?

[Transcriber cannot determine which woman is speaking.]

**HOOYMAN:** The reality is that most women are doing double duty. They are continuing to perform the traditional care-giving roles, but they are also employed, oftentimes in lower paying jobs and jobs without pensions. But they are employed.

So some of the critical ethical issues are that women's plates are getting more and more full. We are trying to juggle more and more. We know that women experience greater stress from care-giving than do their male counterparts, often because women have this great sense of psychological responsibility.

It's a really fundamental issue, I think, when we look long-term at how can care-giving responsibilities be better shared across men and women, and how is our society going to find ways to value care giving.

**KUSZLER:** To just add to that is as women's plates get fuller, their pocketbooks get slimmer; because increasingly, as women become more and more committed to care-giving, they may not even be able to work at the same level that they did before, even if they were—even if they were able to work, their salary was so much lower than men. That's a societal issue that we all have to work on, both men and women, because it's in everybody's best interest to correct those sorts of inequalities.

But on top of this, we see as these women's pocketbooks get slimmer and slimmer, and they get to the point where they can no longer be caregivers, they've spent down—they're now on Medicaid, as Helene mentioned. And of course, when we have our elderly population on Medicaid, guess what? That Medicaid dollar can't serve the young population that's coming up.

So more and more of those, that next generation or two generations down of women, become more impoverished for the generation that they will become when they are now elderly, and they have even fewer resources than the generation before. So it's a constant vicious cycle driving women down, generation to generation.

**STARKS:** I think actually one of the big ethical issues is that intergenerational component. The part that scares me the most is how little we're thinking far in the future.

We should be thinking right now for the babies who aren't born yet, for the girls who have yet to be born. We can't even think about our own selves and our moms and our grandmothers now. What are we going to be thinking about that? Because, precisely, the resource triangle is going in the wrong direction right now. We are absolutely not addressing these issues, so that we're not only making the future more difficult for ourselves, but for the generations that are coming up. And that, of course, makes it harder

for us because we—face it—are going to depend on those who come after us. They are going to be the ones who support us. If we can't do something as a society now to support them, we're in big trouble.

**YOUNG:** I briefly spoke about the case of the Filipino woman who was caring for her elderly mother. One of the big issues in the African American community revolves around grandmothers and great grandmothers taking care of children who are drug-addicted. They've taken care of their grandchildren who were drug-addicted who had children, and now they're taking care of their great-grandchildren who are drug-addicted.

It poses great, immense problems for the caregiver, the grandmother, great-grandmother, but it also poses problems for the teachers in the schools. And the children. I had a principal tell me a couple of days ago that part of the problem is that the children come to school and they're so afraid that when they go home, the caregiver, who is most times older and probably ill with hypertension or diabetes, that this caregiver will be dead or in the hospital.

So teachers have to deal with psychological problems of young children brought about by the social conditions in which these mothers and grandmothers find themselves. At this point I have no idea what the solution is.

But it seems to me that community building and shared responsibility for all children will have to happen in our communities. We are beginning to do some of that in Tacoma at the Evergreen State College. In fact, I have students here tonight, one student is here with her daughter, but we share responsibility for all of the children. There's a girl's math and science program for children there on the campus where their parents attend. They are doing phenomenal work in technology. But it has to be the community. There has to be a community of persons because there are not enough financial resources to take care of these problems.

**HINSCH:** Thank you. In fact, that idea that—and one of the reasons why we are looking at ethics is because ethics is our obligations to others. We think so many of these issues on women and aging need to be framed in that way.

We'd like to move to our audience Q&A portion of our panel. Because this is being webcast, we would invite you to come to the microphone, which is over here to the left. I'd like to welcome anyone who would like to have a question for our panel.

I would also caution that we have a limited amount of time, so if you could frame your questions briefly. We all have wonderful stories to share, but we'd like to do that over wine and dessert at the reception. So I invite you to come forward and ask questions.

—we hope there's more than one who's going to have a question. Be brave! We were!

**AUDIENCE MEMBER:** Well, I can tell my background doesn't mean anything. I thought I knew what I was doing when I got to the mike and used it on stage, because acting in theater is my background! But I—you learn something every day.

I'm glad to be here on this evening. I wanted to state that I think the problem is that when you talk about women of color, I think each ethnic group has its own series of problems. I think it's hard to put a black person up there and ask a black person to speak on what the Latinos may be suffering, Hispanics, or Asians, because they all live in their own separate communities. They all are facing illnesses that other people may not experience because of the environment that they are in. I am talking about, like you could say with blacks, post-traumatic stress, toxic stress. We don't talk about that, those stress factors that incorporate the reason why age is the issue.

So I am saying to you that that is something that needs to be investigated, because even the children in the school environment are subjected to it, even before they reach where we're talking about—little old ladies. So that's where I think that we're in crisis because we want to put everybody in the same basket.

I went to the Latina health fair just to see how they treat each other. What I observed—they do not treat their people like we would treat our people. And the things that may be available to them health-wise are not available to us as blacks. You just need to cut to the chase and tell it like it is. People are not receiving what other people receive. That's why a lot of us are leaving here sooner than other races because we're dealing with that thorn in the flesh, racism.

**YOUNG:** You are absolutely correct, but you have to understand that from my point of view tonight, today, it was very important to get the issue of women of color on the table.

One of the points that I tried to make was that there are differences. There are differences in the cultures. There are differences in the time that people have been in the United States—immigrant populations coming from Mexico have a different culture, have a different cultural experience than those who have been here for three, four generations.

They are very different. They spread out. New immigrants want all the children right around them. You can't move to Chicago or wherever. It's anathema. I really understand what you're saying. You are absolutely correct.

**AUDIENCE MEMBER:** Right. Right.

**YOUNG:** Because we put each other in this big basket. But for the invitation to speak here, I don't know how much about women of color would have even been a part of the dialogue. I have no idea.

I thought it my responsibility to speak not only for African Americans. I am an African American, obviously. But also for other persons of color, partially because I interact with students of color from different backgrounds, different cultural backgrounds and ages

every day of the week. And so I have a responsibility to them, as well. And that is—and since I had the opportunity, I also wanted to include them and address their issues.

**AUDIENCE MEMBER:** Right.

**YOUNG:** But I thank you for your—you are absolutely correct. It's accurate.

**AUDIENCE MEMBER:** All right. Right. It's good. But I'm sure they know that things that affect them are different too. Thank you.

**YOUNG:** Of course!

**HINSCH:** Thank you very much.

**AUDIENCE MEMBER:** Hi. You mentioned, Helene, about morbidity compression. I found that really interesting because I've heard over and over that morbidity is increasing among elderly now, with exactly what you mentioned already—diabetes and heart disease.

I guess my question is, maybe, if you guys could at all discuss the possibility of naturopathic care and the—especially with the poverty issue. It's so much more affordable. If you could maybe discuss that.

**KUSZLER:** Well, of course. Here in Washington we have a great respect for alternative and complementary medicine. Indeed, we are the only state in the Union that actually has a law, the (Any Kind if Any Willing) Provider Act, that fosters health plans paying for alternative complementary medicine.

However, we still come down to the same issue. It is still an area where access, like any other paid services, is going to be an issue.

There's another issue here, however, I think, that underlies this—your concern—and that is I think that in many ways the generation that's in the senior citizen group today is—was brought up during what I call the “era of romance with science,” where many people in that generation, even down to my generation, where we are in our fifties, grew up with a deep belief in technologic medicine.

I think that part of it's an education process that needs to be extended, not only to the non-elderly, but to the elderly population as well, so that they might be more accepting of these new techniques that really can provide them with much more comfort, better care opportunities, and more support, perhaps than a more traditional technologic medicine is going to be able to do.

**AUDIENCE MEMBER:** It's especially—I just want to make a point—more affordable so it sounds like that was foremost in a lot of your discussions, so—

**STARKS:** I think the other piece is that, you know, this is a great topic for SAGE, because I think that there's very little information about what alternative medicines do, really, in terms of outcomes across the life span. I think there are becoming now more clinical trials, where we are developing the evidence base. But I think probably the enrollment issues for doing those kind of clinical trials are not reaching out to older adults, would be my guess.

What I know about alternative medicines at this point is that there's a great deal of interests but it—most of that is driven by those who present for care. This is not the sort of thing that has been widespread in terms of the social uptake, if you will, among older adults.

So it may be the next generation where we begin to see the effects of alternative medicines, and the idea of compression of morbidity may become even stronger if the generations now who are using alternative medicines as their way of managing their health issues—I mean, I think it's a really interesting question for the future, but I would argue that right now we probably don't know enough to say one way or the other.

**KUSZLER:** There are actually some very interesting studies that look at immigrants from other countries where they have a deeply imbued tradition of traditional medical practices. What most of those studies have found is that those folks to emigrate with those deeply held beliefs in a certain style of medicine, which we might call complementary and alternative medicine, generally uptake traditional technologic medicine, but maintain their interest and their use of complementary and alternative medicine, as well.

**AUDIENCE MEMBER:** Have you found that their morbidity is less than—?

**KUSZLER:** I don't think there have been any studies done on that. It would be a great topic though, wouldn't it?

**AUDIENCE MEMBER:** All right. Thank you.

**HINSCH:** Thank you.

**AUDIENCE MEMBER:** All right. I have a question concerning advice. I have a lot of women in my family—I have three sisters and we are starting to have children. My question is, what are the practical issues that I need to take home to them? What conversation do I need to have to say, "These are some issues that you should be thinking about." So when I go home, what do I tell my mom? What do I tell my sisters? What do we plan to tell our children that, practically speaking, they need to think about?

**HINSCH:** Thank you, Nicolle. The question was—we've outlined a number of issues that women are facing as we age. She asked for specific advice—what should she tell her mom? What should she tell her daughters? What should we tell each other as we face these issues moving forward?

**HOOYMAN:** I would tell them to insist that the men in their lives assist with care-giving.

*[Laughter and applause]*

You know, whether it's caring for the children or for older parents or any other family member who needs care—I would also say that when you seek employment and you—to push as hard as you possibly can to make sure there are retirement pensions. Even though increasingly there are fewer and fewer companies that provide private pensions, and women are more often employed in the small companies that don't.

**HINSCH:** Great advice. Beth?

**AUDIENCE MEMBER:** My name is Beth Rosenschein. I am an electrical biomedical engineer, and I came here tonight because I saw that you are talking about ethical implications.

One thing that's very, very important to me is women's health care, specifically around menopause.

I have a book that I've written—it's coming out in the fall. It addresses menopause, which is actually ovarian failure, and all of the negative health effects of ovarian failure, and how it affects our care-giving ability, our ability to have an income, relate the impact it has on our relationships, our sexuality.

One of the things that I don't understand is in the book I write very specifically about how ovarian failure can be prevented, which means that we can prevent menopause for a woman's lifetime, which essentially what I'm saying is we can postpone organ failure. I show very specifically and very specific ways that this cannot be escaped—that this is a medical treatment that is available, and yet it is not offered to women.

I think that, ethically speaking, why isn't it offered to women? Why is this not even on the table? Why isn't it even considered as an option? I mean, it would have to be something that a woman would have to do proactively. It's not something that just would happen. What—just does happen with all of us as we age, all of our organs will eventually fail. So this would require treatment. So ethically speaking, why is this not on the table?

**HINSCH:** Beth is raising a very interesting issue, and actually challenging the concept of menopause and suggesting that perhaps this is not something we need to succumb to. And so she has asked, what are some of the ethical issues.

It's probably—might be too large of a topic for our panel but we'll see if any of our scholars want to weigh in.

**KUSZLER:** I guess that's me. I think that the reason it's not being addressed is that what you refer to as ovarian failure has long been considered by society and by traditional medicine as normal aging. As a result, we really wouldn't need to change the entire cultural approach to menopause to be one of disease where we were going to be correcting an organ failure.

Now, that may be—that may be a viable alternative. But I do ask you to take this into consideration: one of the primary problems we have in the United States is that we have medicalized many of our social issues to such a level that we no longer can tell the difference between something that needs aggressive technologic treatment and something that we should really handle in a social construct. As a result, that feeds our health care cost problem, which furthers our constant difficulty and the vicious cycle that I talked about of intergenerational poverty and inability to get even the baseline of care.

So while I'm very sympathetic to this—don't get me wrong! I also see the opportunity cost of this as being extraordinarily high.

**AUDIENCE MEMBER:** The opportunity meaning the medical treatment?

**KUSZLER:** In the sense—if we do change the culture and throw—consider this an organ failure, what things will we no be able to do as a result? (There will be many things we can do of course.)

**HINSCH:** I think there are many women who'd be interested in talking about this—

*[Laughter]*

—who can find Beth at the reception. We have time for two more questions? I would ask if you could be brief so we can get done on time. Yes, ma'am.

**AUDIENCE MEMBER:** Hi. My name is Leah Walker and I am a student at the Evergreen State College, Tacoma Campus, focusing on law and public policy and social service. As a mother of an asthmatic—chronically asthmatic teenage girl coming from a low-income background myself, and now living at poverty level, society just doesn't allow a person in my position, or persons in my position, to remain gainfully employed and cared for or hospitalized.

Is this a contributor to our long-term financial inadequacies?

**HOOYMAN:** Absolutely. That's again one of the things that has to shift—we need to find ways to attach economic value to care-giving so that the important work you are doing with your daughter, that you are somehow compensated for that or at least are not penalized. We see those—the penalties come through in lower Social Security, for example, because you were not as employed as long. It is just a profound issue that you know—your story really illustrates the complexities that you're the one who needs to provide that care, and yet it's going to hurt you financially.

**AUDIENCE MEMBER:** Thank you.

**STARKS:** I think there's another point to this. We think of ourselves as Americans as family-friendly. I have to tell you that we have very few policies, and very few economic supports, that are family-friendly.

We compare ourselves to any other industrialized nation. We are at the bottom of the list on every single indicator, every single one. So you think about a place like France that pays women up to two years of money to stay home and raise their children. Now, that is a social investment in having children and raising them. We do not have family-friendly policies in this country that translate into economic realities for women.

\_\_\_\_\_: Yes.

**STARKS:** In fact, we expect the families to do it all on their own with very little support.

\_\_\_\_\_: Regardless of where they were—where they start from.

**HINSCH:** We can take one more question, I'm afraid.

**AUDIENCE MEMBER:** That was a fantastic question. My name is Zanif Tolen and I just wanted to give you a quick question about—maybe raise your awareness of immigration and how it might relate to women and aging.

Are there any studies or any research being done in that? A couple of points that I was thinking about are that I know that there—for example, to take care of the nursing shortage, there were specific nursing visas made available. Could such visas for care-giving be made available? Could this be a solution?

Also, how does immigration affect aging when there are new immigrants into the United States who have families at home that they want to take care of, or they want to bring their parents here? Are there any solutions to such problems?

**HINSCH:** It was a broad question about immigration impact on aging from a variety of perspectives. I'll let the panel take that.

**HOOYMAN:** I don't think it's a solution. We already do depend a lot on women immigrants to provide the hands-on care in long-term care facilities. They often are so poorly paid and have so few benefits, that their own families suffer and they, themselves, will not be well prepared for old age.

That's where, I think, we really need to have a profound shift in our society seeing that care-giving work should be compensated in some way.

**KUSZLER:** It's a real double-edged sword to exploit immigrants who come to this country to serve our care-giving needs. Once again, we have a double-edged sword here.

Those caregivers, be they doctors, be they nurses, or be they simply caregivers who assist with activities of daily life—when we take them out of their developing country, we leave a void back there. This brain drain, or resource drain, has phenomenal effects on the countries that they come from.

So when I say “think globally” this is one of the areas where we, I think, would be hard pressed ethically to justify depriving a country that desperately needs its own providers and caregivers to serve the needs of our population.

**HINSCH:** Thank you. We have asked each of our scholars to give the Women’s Bioethic Project one policy recommendation that they would like us to work on that would help address some of the issues that we’ve looked at.

I’d like to begin with Dr. Hooyman, please.

**HOOYMAN:** Oh! There are so many! But I think that the primary recommendation I would make is something that is before Congress now, and so you can act on it. That is to extend the Family and Medical Leave Act, so which now only allows for unpaid leave.

But there is legislation to have it become a paid leave. It would be a small step toward the situation that Helene referred to in terms of many other western industrialized countries.

But I want you to leave here with something that you think you can do. So pay attention to that legislation and make sure your Congresspeople hear how important it is that family leave be paid leave.

**KUSZLER:** OK. Well, mine is probably considerably broader. My policy suggestion would be that women have a vested interest in becoming extraordinarily activist about health care reform. When I say health care reform, I mean activist about finding a way so that women’s causes, as well as family causes, are increasingly covered by our health care plans and, if need be, by our tax dollars.

That means we need to be activist about things we may not agree with. When a pharmacy doesn’t fill a young woman’s birth control pill because they don’t feel like doing it because they have a conscience clause, every single one of us should be boycotting that pharmacy! We need to start putting our money where our mouth is with respect to the rights of our sisters—

*[Applause]*

—whether we agree with what they are doing or not.

**STARKS:** I think that the number one thing that we need to look at is universal health care. I think that every day that we can do something to move us closer to the goal of having coverage for everyone from birth to death is vitally important. And in that,

although this will make the cost even more insanely expensive than it is now, we have to include social insurance for long-term care. Long-term care is being paid for now privately mostly, and through Medicaid. They'd have to include long-term care so that we have good care from birth to death.

**YOUNG:** My policy suggestion is a little bit different and a bit more specific. Just as lawyers are required to take ethics courses in law school, and to periodically take continuing education courses in ethics, I believe that it should—there should be some requirement for cultural competency among health-care givers. That includes nursing assistants, doctors, nurses, whoever is a part of the health-care team, whoever is licensed in the state of Washington by the Department of Health, should have some level of cultural competency to deal with the increasing of a growing population of people of color and new immigrants into this state.

**HINSCH:** Thank you.

**YOUNG:** Right.

**HINSCH:** We we're going to end this session with an excerpt of a poem that Dr. Young is going to read.

**YOUNG:** I am reading an excerpt from Maya Angelou's poem on aging that is in *Trials, Tribulations and Celebration*, a book edited by Marian Secundy, the last stanza.

When you see me walkin', stumblin',  
Don't study and get me wrong  
Cause tired don't mean lazy.  
And every goodbye ain't gone.  
I'm the same person I was back then.  
A little less hair, a little less chin,  
A lot less lungs and much less wind.  
But ain't I lucky?  
I can still breathe in!

**HINSCH:** Excellent!

*[Applause]*

Well, with that amazing poem and energy, I'd like to thank our scholars for their generous use of their time tonight to be with us. I'd like to thank SAGE Crossroads, Dan Perry and his entire staff for partnering with us to make this event possible.

I'd also like to acknowledge the Women's Bioethics Project volunteers: Jarna Jane, Gaby Adam, Nicolle Perisho and Christie Ellison, and Nicolle's mother, Carolyn, for being here with us tonight to make this possible.

I want to point out to you that in your notebooks that you've been given there's an evaluation form, and if you could fill that out we'd appreciate your feedback.

There is also a card about how to get involved with the Women's Bioethics Project, and I'd like to invite you to join us in further conversation at our wine and dessert reception in the room to your right outside the door.

Thanks so much for being here, and good night.

*[Applause]*