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## Aging and Disability Disparities

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## AGING AND DISABILITY DISPARITIES

“For people who have Medicare, their out-of-pocket costs are on average six times greater than the out-of-pocket costs for someone with employer-sponsored coverage.”

**Professor Ahaviah Glaser:**\* I am going to talk broadly about health care disparities and older Americans. One of the things that I find most interesting is that as I told people that I was coming to give a talk on health disparities in aging populations I heard, “Well, what are you talking about? Older Americans are the subject of health care disparities?” My jaw dropped because I was having these conversations with very experienced policymakers, staffers, and lawyers who work on health care issues. I thought, “What do you mean?” What do you mean that older Americans do not face health care disparities? By and large these individuals said, “Older Americans have Medicare. They are taken care of.” Therefore, a lot of what I want to talk to you about today is the fact that, unfortunately, although Medicare is a fabulous program, having Medicare does not mean that you have been taken care of.

It also does not take away the other health disparities that have been discussed here today. As soon as you turn sixty-five years old, you do not suddenly stop facing issues with linguistic and cultural competency, for example. You do not stop being affected by the number of physicians serving your community, so on and so forth. Those are sort of the big picture things that I want to look at. The other issue is too often people think of older Americans just as the sixty-five plus age group. In reality, older Americans, at least from the AARP perspective, are fifty years or older. What about fifty to sixty-four-year-olds, who are not old enough to be a part of Medicare unless they have certain qualifying disabilities? How do they get their coverage? These factors unfortunately really do indicate that older Americans are in fact subject to a variety of the health care disparities.

First, I will talk a little bit about Medicare. Here is the shocker: for people who have Medicare, their out-of-pocket costs are on average six times greater than the out-of-pocket costs for someone with employer-sponsored coverage. That figure is calculated as a percentage of income, but regardless, this is a shocking

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statistic. Part of the problem is unlike most employer-sponsored coverage and other coverage in the private market, there is no out-of-pocket cap in Medicare. If you have had a serious medical incident on Medicare you will not reach a point over the course of the year where out-of-pocket expenses cease and insurance coverage kicks in. Medicare has no out-of-pocket cap at all. Also, under Medicare prescription drugs are paid for using what is called co-insurance, rather than co-payment.

I am fortunate enough to have health care insurance coverage. I also have coverage that includes pharmaceuticals. In the last five or six plans I have had, when I go to the pharmacy there is a co-pay. Co-pays are tiered: five dollars for certain generics, maybe ten or fifteen dollars for another generic, twenty-five dollars for a brand name. I know that month after month with my insurance it is going to cost me five or ten dollars for me to pick up that prescription. People on Medicare pay twenty percent of prescription drug costs. If the cost of a drug goes up over the course of the year, Medicare enrollees pay for that. If a Medicare patient fills a 100 dollar prescription, he or she pays twenty dollars. If it is a 500 dollar prescription they pay 100 dollars. These high costs are not uncommon. I would encourage you to take a look at your local CVS clinical cost. You are only paying a tiered co-pay, but people on Medicare would pay a percentage. The same rule applies to fees at the doctor’s office. I pay a twenty-five dollar co-pay when I go to the doctor, but it could be much, much higher if you are on Medicare paying a percentage of the actual cost. By and large, percentage of income has traditionally been a good way to look at health care costs. For example, at AARP we suggest that no one should spend more than ten percent of their annual income on health care costs. Under Medicare, the average beneficiary spends a minimum of thirty percent of their income on health care expenses. The oldest and poorest of Medicare beneficiaries spend more than half of their annual income each year on health care.

Medicare, although it is very important and very well thought of in a lot of different ways, does not cover costs such as eyeglasses, hearing aids, dental care, or preventive services, not to mention, most long-term care services. If a Medicare beneficiary needs to be in a nursing facility for longer than 100 days, Medicare will not contribute to those costs. There is

also an enormous coverage gap in the Medicare Part D prescription drug coverage benefit. The good news is that under Part D, Medicare now does cover prescription drugs other than those drugs that you get in your doctor's office. The bad news is that there is currently a 2,500 dollar gap in which enrollees get no assistance with drug costs. That 2,500 dollar gap will be a 6,000 dollar gap in another two short years. You can imagine what a 6,000 dollar gap in prescription drug coverage could mean for those with significant pharmaceutical needs; especially given that fifty percent of all seniors in the U.S. make 20,000 dollars a year or less. A lot of people who rely on Medicare and even Medicare with supplemental coverage are stuck with enormous costs that sometimes result in not getting the coverage they need.

Although others today have talked about racial disparity issues, there is a racially-related access issue in terms of finding a doctor near your home that takes your policy. Although lots of doctors do accept Medicare, there are simply not enough who do, particularly to support the aging baby boomer population. Many doctors are concerned with Medicare reimbursement rates for physicians. There is disagreement about this and I am not going to get into that today, but absent Congressional action, Medicare doctors are going to face a twenty-one percent decrease on March 1st and one can imagine that would only exacerbate this particular problem.

The last thing I want to mention, in terms of Medicare not necessarily being everything it should be for seniors, is financial assistance programs within Medicare are severely limited. Financial assistance programs under Medicare really only help those just above the poverty level (for those of you who have studied federal poverty issues, the poverty level is quite low and quite understated). The program is designed to punish those who have even a small amount of assets. If an individual has saved at all for retirement, if he owns the property where he lives, if he receives a small, even 1,000 dollars, insurance benefit when his spouse dies, he may become ineligible for Medicare's financial assistance programs.

The fifty to sixty-four year-old age group is a really interesting group because if they have employer-sponsored insurance, they are just as fine as anyone else might be. However, there are many people in this age group, about nine million Americans at the last count, who do not have employer-sponsored coverage. They are up a creek without an oar because depending on where these individuals live, there will be one of two results. There are parts of the country where there is literally not a single policy available for sale or application if you are in the fifty to sixty-four age group. Insurers have decided that it is not a particularly profitable market and they stay out of it. Therefore, the first possibility is that even if a fifty to sixty-four years old wants insurance, there are no policies to apply for.

The other possible outcome, for those living in areas where they can apply for a policy, is cost prohibition. Non-employer-based policies for fifty to sixty-four years olds tend to be prohibitively expensive; usually at least double the cost of an employer-sponsored program. There are even states in this country where a person fifty to sixty-four years old pays fifteen to twenty times what a younger person would pay for an identical policy regardless of their health status. There is a fundamental access to health care issue here.

To top that off, very often these policies are not comprehensive. It brings to bear this question: will your insurance actually cover you when you need

it? Very often the answer is no for people enrolled in these policies. To add insult to injury, seventeen to twenty-eight percent of all applicants in the fifty to sixty-four-year-old group are rejected when they apply for available policies. Typically, rejection is based on what is called a pre-existing condition.

Rejection of coverage based on pre-existing conditions has been the subject of much debate in health care reform in the last year or so—or the last thirty years depending on how you look at it. The end result is that people in this age group, who have been losing jobs at a much higher rate than younger Americans in this recession, are in a lot of trouble and rarely have access to good comprehensive care. Last but not least, other health disparities problems are simply compounded for senior citizens. The health disparity issues they might face due to race, gender, disability issues, sexual orientation and all of those things do not go away. When you turn fifty or sixty-five, these problems do not evaporate.

Seniors, in more set-upon populations, can really struggle paying for health care coverage. Thankfully, we have solutions for all of these problems. By and large, it is a matter of implementation. We need to put an out-of-pocket cap in place. We need to eliminate the asset tax for financial assistance in Medicare. We need to raise the physician reimbursement rate particularly for general practitioners and gerontologists to ensure that they get into all the communities that need their services. We need to close the coverage gap in the Medicare Part D prescription program.

In terms of insurance market issues, these are fairly straightforward. Ideally, all insurers should be required to use community rating, which is the true spreading of risk in the traditional sense of what it means to have insurance. All insurers should be required to offer policies with comprehensive benefits. It will ensure that whoever is purchasing a policy is actually getting something for her money. It will also allow consumers to compare apples to apples to determine what policy they want to purchase on the market. We also need to eliminate the pre-existing condition barrier to obtaining health care coverage. This is an issue that has a lot of support on both sides of the aisle in Congress, but we do not have time to discuss it here. It has been very difficult to actually end denial of coverage based on pre-existing conditions.

In terms of general health disparities issues and what we can do: first and foremost we need to continue to collect data about health disparities. The reality is we need to be able to find solutions and do things wisely. Governments will typically not move without an awful lot of information, so we need to develop that information. We also need to put resources into enforcing existing civil rights laws within the health care context. This is an area lacking in funding and resources and I really feel strongly that investment in civil rights issues could impact health disparities by addressing issues with cost and access.

I say, as a matter of regular course, all medical providers should receive at least some level of cultural competence training and foreign language translation services should be readily available at all health care facilities. This is an issue that seemed an unimaginable problem twenty years ago, but today we have the resources where at least telephonically, no matter where a patient is in the country, he or she should have access to a trained medical translator in any language. Last but not least, I think that it is important to

provide incentives to bring providers into underserved areas to work with underserved communities.

That concludes my overview. The headline, of course, is unfortunately, older Americans, in particular, suffer from health care disparities.

**Chris Herman:**\* My name is Chris Herman and I have been with the National Association of Social Workers (NASW) for four years. To give you a sense of where I come from, before I worked in NASW, I had more than a decade of social work practice experience in aging and disability settings, such as hospice care. Most of my experience is here in the Metro-DC area in people's homes, and also sometimes in assisted living and nursing facilities, because you can actually get hospice in those settings. I have worked with adults with multiple sclerosis—people who were in their 20s, 30s, 40s, like some of us in this room—whose lives were changed instantly with the diagnosis that, for many people, is progressive and can be debilitating. I also practiced geriatric care management that tended to be with a lot of what are sometimes called “older adults”—people more than seventy-five or eighty-five years old—and many of them in their homes, struggling just to stay independent. Often times these older adults had very limited social support or had out of town family caregivers. This practice perspective really influences the work I have been doing on a more macro level in developing resources for social workers and other professionals around aging and disability issues.

I am really pleased to be here and to have a chance to collaborate with those from the legal discipline. It is essential that we work together as professionals both on a practice level and on a policy level to achieve some of the changes to which other panelists have alluded. I was asked to address challenges related to aging and long-term care or, as is more commonly coming to be known, long-term services and support. Just a brief word of explanation: “long-term services and support” is a term that is very common in the disability community. Aging advocacy organizations can certainly appreciate the perspective that the need is not always about care, but about getting the services and support that people need to maintain the greatest level of independence in whatever setting they live. This is not to say that “long-term care” is not an appropriate term to use, but you may start hearing both terms more and more.

Even though I am going to focus on challenges associated with aging, I think it is essential to preface my remarks by expressing two perspectives that are inherent in social work practice. One is a person in environment perspective. The key to this perspective is that we can only understand and help improve an older adult or any person by exploring and addressing the social context in which that person lives or has lived. This perspective assumes that racism, ageism, sexism, homophobia, and other biases underlie and perpetuate health disparities both on individual and societal levels.

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The second perspective is the strengths perspective. In the aging and disability context, this perspective focuses on the resources, abilities, and contributions to society, economically and otherwise of older adults and people with disabilities. This perspective is very important because although it is great that there is so much more attention now being given to the aging of baby boomers, there can tend to be a catastrophic tone to aging. There are pitfalls to looking at older adults as disadvantaged. Such a viewpoint can lead to perceiving older adults as a burden to society and long-term care systems. Although societal aging does present challenges that we have to deal with focusing only on the challenges creates the danger of blaming the problem on the people involved rather than on the system. The strengths perspective also emphasizes collaboration with older adults and people with disabilities, which is really critical if we are going to eliminate disparities. These populations know firsthand what their experiences are and often what the solutions need to be. Also, we need greater collaboration with family caregivers. It has been very rare in my experience to work with older adults, and to some degree with people with disabilities, without also interacting with family caregivers. I mean “family” in the broadest sense of the word; whoever is significant to that person and provides support in various ways (physical, economic, emotional).

First, I will talk about older adults as a cohort and how they perceive the differences between older adults and younger adults. Much of the data that I have is from the Administration on Aging which tends to focus on people sixty years and older. Older adults are more than twice as likely to be diagnosed with two or more chronic conditions as their younger counterparts. Having two or more chronic conditions is associated both with lower income and fair to poor self-reported mental health. Almost thirty percent take five or more prescription medications concurrently and about half of that group also uses over-the-counter medications and dietary supplements. This is not always addressed by older adults or health



care practitioners, but it can certainly complicate the picture. As a whole, older adults are more likely than other age groups to be living with serious health care conditions and taking a lot of medications to treat them. At the same time, older adults tend to have lower health literacy levels than younger adults. Also, the health care system is becoming increasingly complex to navigate for all of us regardless of age. Furthermore, the health care profession has struggled to retain qualified workforce to serve older adults.

A 2008 Institute of Medicine (IOM) report,<sup>1</sup> “Retooling for an Aging America, Building a Health Care Workforce,” highlighted two critical needs. One is the need for more health care professionals, such as physicians, nurses and social workers that specialize in gerontology. There is a general need both for more Medicare providers and for providers with specific geriatric training. In social work, only about nine percent of our workforce specializes in aging, and that is much less than we need. Also, the report highlighted the need for more training in geriatrics and gerontology across providers regardless of setting. There are social workers, for example, working in child welfare who wind up interacting with the grandparent who is raising the child. The next thing you know, the social worker is facing aging issues he or she may not be familiar with. The grandparent may have his or her own health care concerns or social service needs. Even though we need specialists, none of us can afford to know nothing about aging. The IOM report also described the need for enhanced support of and training for family caregivers. It is encouraging to know that the IOM may do a report on the mental health workforce at some point. Mental health needs, which are great, are often left out in health care discussions. NASW and many other mental health advocacy organizations support such a report.

Lack of workforce is not the only challenge that older adults face in getting access to mental health services. There has been a lack of parity in reimbursement for mental health services. This has been the case in many commercial insurance plans as well. Specific to Medicare Part D, when it comes to outpatient psychotherapy services enrollees must pay fifteen percent of the cost of treatment. This makes mental health services a lot less affordable. Fortunately, in 2008 Medicare legislation was passed that reduced beneficiary cost sharing from fifty percent to twenty percent over a five year period. There is a decrease in the co-insurance rate each year. This will make mental health services much more affordable for older adults. It has been a long time coming. It is also important to know that Medicare mental health

providers, such as clinical social workers and clinical psychologists, are affected by cuts to Part D benefits and reimbursements, which makes it harder for older adults to find practitioners who can provide mental health services under their insurance.

Shifting to disparities among older adults, I am going to talk briefly about women, LGBT individuals, families, and racial and ethnic minorities. For each group, there are economic challenges to accessing high-quality health and long-term care. Some studies have shown that assisted living communities—despite affordability initiatives and Medicaid waivers that cover a portion of services—continue to be disproportionately located in areas with higher wealth, higher educational attainment, and higher housing ownership.

There are also private-pay services that enable an individual to maintain independence at home. A Home health aide services often get very little coverage from Medicare, so many people have to pay out of pocket to get that type of care. Affordability of such service is a particular concern for women. Women constitute almost sixty percent of the population age sixty-five years and older. Women eighty-five years and older outnumber men by about two to one. In general, women have less money to meet their long-term care needs. The median annual income in 2008, for example, was \$25,000 for older men and \$15,000 for older women. It is no surprise then that older women are nearly twice as likely as older men to live in poverty. Older women are also more likely to live alone than older men, which increases their risk of poverty. Again, it comes as no surprise that older women constitute about three-quarters of nursing home residents sixty-five years and older. The poverty rates are especially high for African American and Hispanic Latina older women living alone. Economic security is related to lifetime history of wages and benefits such as pensions, Social Security benefits and other savings. Older women also tend to live longer than men. They are more likely to report at least one functional limitation in old age.

In terms of LGBT aging, lack of visibility ranges from lack of inclusion of health care forms and research and data collection and that invisibility is reinforced by lack of cultural competence among individual health and long-term care providers within the systems. These dynamics reinforce a sense of stigma that has keeps many LGBT individuals in the closet throughout their lifetimes. Especially in old age it is not uncommon for people who have been open about their sexual orientation all their lives and then move into a residential care setting to go back into the closet for fear of the reactions they are going to get from their peers and the providers in the setting. This invisibility

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and lack of respect extends to relationships. Some states limit hospital visitation and there is a lack of recognition for care giving relationships by partners or other family of choice under the Family Medical Leave Act. Workplace discrimination throughout the lifespan is especially rampant for LGBT people because of the lack of federal employment discrimination protections based on sexual orientation and gender identity. The Employment Non-Discrimination Act would change this.

There are some hopeful signs of progress. The Administration on Aging has designated funding to create a national LGBT aging resource center which is very exciting. The IOM is conducting a study on LGBT health issues and research. This study is not specific to aging, but hopefully, but will hopefully yield some information that is relevant to LGBT older adults.

I want to sum up my remarks with a couple of notes on race and ethnicity. Poverty is very rampant among older adults of color. African American and Latino older adults are about three times more likely to live in poverty than older White adults. Health outcomes and access to services are also lower for African Americans and Latino older adults. For example, research has shown that African Americans are more likely to live in lower quality nursing homes than Whites. In conclusion, we need action on policy and practice levels to address health disparities between older adults and other age groups. Cultural and linguistic competence is essential to reducing disparities among older adults. Finally, we cannot succeed in any of these efforts without engaging older adults and family caregivers.

**Daniela Kraiem:**\* All of us know someone or are related to someone, or perhaps even are someone who requires long-term care or long-term supportive services. Two years ago, the federal government promulgated regulations which allow a new delivery system option for people who receive federally funded long-term care through the Medicaid program. This delivery system is called “Consumer Directed Care,” or as it is more commonly known, “Cash and Counseling.” It is not an entirely new idea, but it was previously available only in small pockets as an experimental program, or through funding by states or localities. The new regulations allow large scale

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federal funding of this delivery system for long-term care. My talk today is about some of the issues raised by these recent regulatory changes.

“Cash and Counseling” amounts to an individual account that a Medicaid recipient can use to purchase goods or services for their long-term care. This option is in lieu of having Medicaid pay for a person live in a long-term care facility like a nursing home or having Medicaid pay for long-term care through an “Agency” model system in which contracting providers send long-term care aides into people’s homes.

What is new and different about “Cash and Counseling”? The cash part is a major change in policy. Medicaid will now provide an individual account that a Medicaid recipient can draw from to pay for a long term care worker of his choosing. Basically, this cuts out the middle man—the agency. Money (in the form of vouchers) will flow more or less directly to the beneficiary who then pays the home health care worker. The beneficiary can also buy some goods or services with these funds, although today I am going to focus on long-term care aides.

The counseling part of “Cash and Counseling” comes in the form of training or assistance in how to hire, fire or train a long-term care worker. Most people are not used to being employers and many require some assistance in figuring out what they need to age in place. Most of the states that have already implemented “Cash and Counseling” wound up serving as fiscal agents for the beneficiary. The state cuts the checks to the vendors and manages withholding and employment taxes, even though the consumer is the employer.

There are several reasons why states started to experiment with this program, and why the federal government is allowing its adoption on a larger scale. The first reason is that it increases the autonomy of the beneficiaries who choose their services, and hire, fire, and train their own aides. Instead of having an agency deliver care, people are going to choose and direct their own care. This pleases fiscal conservatives, who see this as part of the “ownership society” promoted during the presidency of George W. Bush. It also pleases members of the disability rights movement, who have righteously struggled for many years to assert the capacity of persons with disabilities to control their own lives. To be clear, I am not talking about theoretical questions of autonomy and self-determination, but very specific, extraordinarily intimate decisions. We are talking about being able to choose the person who comes into your home, perhaps helps you to dress, eat and prepare food, and who may assist you with the most intimate bodily needs.

The second reason for consumer direction in Medicaid funded long-term care is that, as other panelists at today's symposium have suggested, there is a severe shortage of direct care workers—including in-home long-term care aides. There is a crucial shortage of these direct care workers already, even long before the members of the large baby boom generation starts to require long-term care in great numbers. Because beneficiaries hire their workers directly, consumer directed long-term care addresses the labor shortage by opening up new pools of workers: people who might be willing to care for a friend or relative for pay, but who are otherwise uninterested in long-term care work.

In the pilot programs, consumer direction had an interesting side effect, which I suggest must be considered part and parcel of the program. Under the original system, a family member was very unlikely to become a paid caregiver. You were not going to hire yourself out to an agency where you could be sent to any consumer, if what you intended was to care for your aging mother, mother-in-law, or spouse. Also, under the old rules, legally liable family members, such as spouses and parents, were not allowed to become paid caregivers under most circumstances. With "Cash and Counseling," aging adults or persons with disabilities can easily hire their own family member, including those in the same household, to care for them. In the pilot programs for "Cash and Counseling," somewhere between sixty and eighty percent of the people enrolled in the programs picked a family member to provide their care. I have no conceptual problem with that, and I certainly believe that all caregivers should be compensated or remunerated in some way, but I wonder what kind of transformations this could create in both family life and long-term care more generally.

My larger project is to analyze critically the shift in policy. I will give only a rough overview of some of these concerns today. While "Cash and Counseling" has some real benefits, it also carries with it hidden costs that we need to be cognizant of if we are going to

move on a large scale towards this model. Briefly, my concerns can be categorized into three areas.

The first is the focus on autonomy. The autonomy discourse, transforms the Medicaid beneficiary, typically a lower income person with long-term care needs, into a "consumer." The "Cash and Counseling" pilot programs self-consciously do not call enrollees "recipients," or "beneficiaries" which is what they are typically called in Medicaid, but calls them consumers. For those of you in the health care field, this may be reminiscent of the consumer directed model in health care. On a much larger, philosophical level, this starts to equate social citizenship with only the ability to consume.

Second, this emphasis on the autonomy of the individual emphasizes individual solutions in which each person is responsible for his or her own long-term care decisions. While that can be very beneficial in some cases, it hides some of the structural nature of problems faced by the elderly or by people with disabilities, particularly issues related to other biases, like race or gender. It hides the disparities in the health care system by making it seem like each person has the same resources to solve the challenges of long-term care—when in fact, we know that people arrive at the need for long-term care in very different situations, with different constraints, resources and abilities. The emphasis on individualism also blinds us to the possibility of creating solutions inside of our communities. One of the things that we know is that when you are assisting a person who wants to age in place, for example, you are very rarely dealing with just that individual. You have to take into account his family and community, as broadly construed. An emphasis on individual thinking leads us away from pooled or collective solutions to problems.

My third set of concerns centers on how consumer direction might reinforce disparities, not just within the health care system, but within society at large. I am most interested in the relationship between long-term care workers and the consumer or the beneficiary of the services, and what the legal and social ramifications of the transformation of the employment relationship away from an agency model to a consumer directed model might be.

Why are race, class and gender disparities important in this discussion? Long-term care workers are part of the low wage workforce. They are ninety percent female. They are disproportionately women of color. They work without the protection of federal minimum wage or maximum hour laws. They work with minimal, if any, OSH protection. They receive very

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spotty Workers' Compensation coverage, which is especially disturbing given the very high rates of on the job injuries on people who do the very physical labor of caring for other bodies. They earn on average somewhere between eight and ten dollars an hour. They have extremely low rates of health insurance. Many live in families who are eligible for public assistance, which tells you a little bit about their economic status.

It is no wonder we have a labor shortage in this field, which is oddly immune to the laws of supply and demand. Wages do not increase in this field, notwithstanding the shortage of labor. There are a couple of reasons for this. There are non-regularized workers in this field. In the private market, this is largely immigrant labor, and to a degree that we are not exactly sure of, although we are certain that it exists, undocumented immigrant labor, which puts downward pressure on wages. The other reason, of course, is the unpaid care giving performed by family members, largely women. The approximate dollar value of unpaid care in the US is around three hundred sixty billion dollars.

My concern, which I am only touch on very briefly here, is that this program splinters the employer—an agency, a big entity—into many individual consumers. In doing so, we reduce the ability of long-term care workers to engage in collective action or bargaining, which has been effective in raising wages. We will have a pool of workers, whether they are family members or not, who are unlikely to band together to raise dismal wages and improve dismal working conditions in these programs. In addition, workers who are employed in private homes lose most of the even minimal labor and employment protections. Given that these workers are overwhelmingly low income women of color and/or female family members, we have to stop and question whether consumer direction in fact reinforces race, class and gender-based disparities, albeit unwittingly.

I want to be very clear that I believe that consumer direction has real virtues. In particular, it places the dignity and self-determination of people with disabilities at the center of the discussion. It emphasizes that the elderly and persons with disabilities can and should exercise control over their own lives. My cautions and concerns, however, are warning flags of ways in which consumer direction might reinforce disparities and inequalities in the low wage work for or in family life. However, I do not assume that this must be the case, and I hope to see more policies in the future which take into account the needs of caretakers as well as beneficiaries.

**Participant:** I found it fascinating learning about the “Cash and Counseling” program. I am concerned that we have older adults who do not have a family complex. Where a person is just an individual we would have to go to the physical agent model, which means we are back in the old system again.

**Daniela Kraiem:** The “Cash and Counseling” program is designed is to be an option. States that participate are required also retain the other model. It is very clear to me from the data of demonstration studies that your point is correct. If a person is not already embedded inside a care giving community, the odds of her being able to hire her own worker are close to zero. One of the big problems is where to find a worker. Agencies have this problem too. The “Cash and Counseling” program does allow people to find workers that the agency could not find. If you have access to family members, or are a member of a church community, for example, you may well have an easy time finding a worker. If you are not already embedded in a care giving community, this is not a program that is going to work for you. The creators of the program did recognize that and the agency model will continue to exist for those people

**Participant:** At one time I organized caregivers in the State of Maryland. The workers are so dispersed that nobody knows each other. It is easy to organize when people work together, know that they have the same needs, and can discuss issues amongst each other. The workers were not very invested in organizing because they do not really understand the need. What efforts are being made in this regard? Most of the people we worked with actually were not family members. They started in the field because they had family members that needed care givers, and then they realized they could make some side money working for others. Being a care giver was something on the side for multiple people. They would make sure to check on four different people, for example. What is being done to get states involved so they can provide a different work environment for this entire industry?

**Daniela Kraiem:** Organizing care workers of any sort—this is true in childcare as well—is difficult. It is one of those fields where you have a tendency to grow very attached to the people for whom you provide care. Organizing these workers is notoriously difficult. There have been some very successful efforts at organizing long-term care workers and childcare workers also, most notably in California. In that state actually, in-home supportive service workers have an option of joining a union and they took the strategy



of organizing worker centers to do exactly what you talked about, actually bring people together. They created workers' centers, a place where people would come to have meetings and to get training. This was done so that California long-term care workers would get to know one another and form a kind of a collective community. Once together, these workers could look at the fact that they were all making eight dollars an hour and trying to live on that in Los Angeles County, which is an expensive place, and agitate, in some cases very successfully, for increased wages and better working conditions. Workers have actually gone so far as to agitate for increased benefits for the people they work for.

In California, despite the state's fiscal crisis, the in-home supportive services workers union, which is quite active, have fought the governor on across the board cuts to long-term care services. This was done to keep members' jobs, but also on behalf of beneficiaries. I think "Cash and Counseling" actually undercuts that potential. Once you are working for an individual beneficiary, you cannot get more money in the pot. If an individual given a set benefit the worker cannot ask for more from their employer. The employer is a poor person *by definition*, because they are enrolled in the Medicaid program. When there was an agency, workers could lobby the state for additional funds for the system as a whole, which would then trickle down to them. Collective action was possible. With individual beneficiaries serving as employers, the workers lose the ability to organize, and what we are going to see is really bad wages and difficult working conditions frozen, with very little potential for improving them.

**Participant:** I have a quick question about the "Cash and Counseling" program when it comes to existing difficulties in establishing care in rural areas or in the mental health field where there is even less access to long-term care workers. Do you think that it is possible to address those issues under the current program?

**Daniela Kraiem:** The rural question is a really interesting one. Despite all of my reservations about "Cash and Counseling," I think that in the rural community it works quite well for some people. For example, in New Mexico, where I am from, few people live in the city and the rest of us all live out in the country. Particularly on the Native American reservations, there are huge distances between communities. A care worker could not serve three different clients because they all live eighty to ninety miles apart. Therefore, in rural communities, the ability to have a local worker, as well as bring some cash into what is probably a very cash-poor household through "Cash and Counseling" can be quite beneficial. For rural communities this kind of program can work very well.

On the mental health front, there is no one size fits all answer. While families are places of safety and refuge for a lot of us, for others they can be difficult spaces. With mental health issues those problems are often magnified, particularly if you are going to combine mental health and substance abuse in families. Keeping people ensconced within their family, may not be the best option for either the beneficiary or the family. On the other hand, it may be possible to meet the needs of a person with a mental illness through consumer directed care. One issue that bears watching is the question of consumer direction and dementia. Caregivers for patients with dementia report the highest levels of stress of all caregivers. Consumer direction may help some of these families, while it may create additional burdens for others. From the point of view of the families and the beneficiaries, choice about the type of delivery system and type of care are crucial.

<sup>1</sup> *Retooling for an Aging America: Building the Health Care Workforce*, INST. OF MED. (2008), available at, <http://www.nap.edu/catalog/12089.html>.