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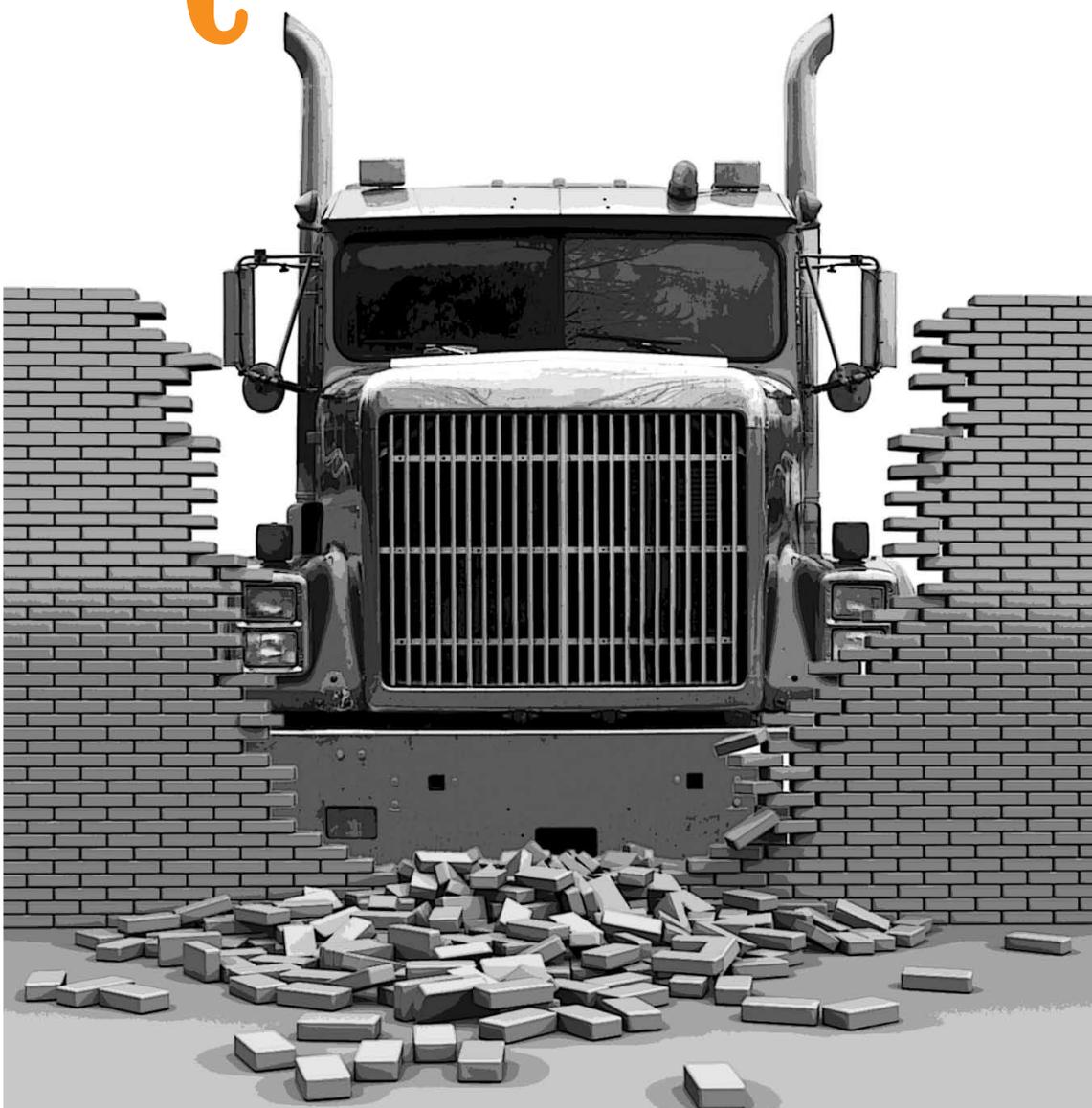
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OLDER WOMEN OF COLOR *and the Challenge of* REGULATING CULTURAL COMPETENCE

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In communities of color, older women are a particularly precious resource, relied upon to transmit cultural values to the younger generation and, in many cases, to rear or contribute to the rearing of their grandchildren and great grandchildren. In Asian, Hispanic, and African American communities, elders are much respected and a rich source of cultural continuity; they form the bedrock cultural identity on which dislocated families can build their future. Their role is both cultural and practical as they fill in gaps in struggling and burdened families. Programs ensuring that these women can age in place to the maximum extent possible and maintain their connections to family and community not only offer them the dignity and care that they deserve but also strengthen the fabric of the neighborhoods and families in which they live.

Yet older racial and ethnic minority women also are poorer, sicker, and more dependent on public benefit programs than their white peers. Many have limited proficiency in English. Cultural competence, language access, and attention to the unique needs of racial and ethnic minority communities are key factors in the success of programs serving older women of color.¹ Here we look at the characteristics of older women of color and discuss one benefit, the delivery of personal care services under Medicaid,

¹There is no standard definition of "cultural competence"; however, the definition used by the U.S. Department of Health and Human Services (HHS) is appropriate for this discussion: "cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations" (Office of Minority Health, U.S. Department of Health and Human Services, *What Is Cultural Competency?*, www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=11 (last modified Oct. 19, 2005)). See also National Center for Cultural Competence, Georgetown University Center for Child and Human Development, www11.georgetown.edu/research/gucchd/nccc (last visited May 17, 2009). For discussions on cultural competence for attorneys, see Tammi Wong, *Race-Conscious Community Lawyering: Practicing Outside the Box*, 42 CLEARINGHOUSE REVIEW 165 (July–Aug. 2008); David Hall, *The Challenge of Diverse Leadership in Legal Services*, 41 *id.* 629 (March–April 2008); Mayia Thao & Mona Tawatao, *Developing Cultural Competence in Legal Services Practice*, 38 *id.* 244 (Sept.–Oct. 2004).

for which regulations released in October 2008 are among the most explicit to date incorporating themes of cultural competence. Some of those regulations, governing self-directed personal assistance services, have specific mandates to accommodate cultural preferences and language needs and to give beneficiaries options to choose providers, who may be family and part of their own community.

The regulations, issued by the Centers for Medicare and Medicaid Services (CMS), give advocates new ammunition to press for improvements in language access and cultural competence at the state and local levels to make the personal care services program work better for low-income women of color.² Advocates may also want to consider the extent to which these regulations might be good models to use when seeking to strengthen the regulatory underpinnings for effective benefit delivery in other programs and whether these regulations might suggest fruitful directions for future advocacy.

I. Characteristics of Older Women of Color

Older women of color are part of a demographic trend in which the percentage of racial and ethnic minority elders will increase from less than 20 percent of the

U.S. older population in 2010 to about 40 percent in 2050.³ The Hispanic population is expected to increase most rapidly to more than seventeen million (20 percent) in 2050.⁴ The older Asian population will increase to almost seven million (8 percent), and the population of black seniors will increase to almost ten million (11 percent).⁵ As discussed below, older women of color are more likely than older white women to be poor, be living with family, speak a language other than English, and have poor health indicators.

A. More Likely to Be Poor

By every measure, older women of color are more likely than their majority counterparts to be poor. More than 20 percent of older black and Hispanic women live in poverty.⁶ Even if they are still working, older African American and Hispanic women are more than twice as likely as older working white women to be poor.⁷

Most racial and ethnic minority elders, both men and women, with incomes below 200 percent of the federal poverty level struggle economically. Almost 70 percent of elderly Hispanics, more than two-thirds of elderly African Americans, and more than one-half of elderly Asian Americans have incomes below 200 percent of the federal poverty level.⁸ By con-

²Recipients of federal financial assistance through the Centers for Medicare and Medicaid Services (CMS) are already subject to limited-English-proficiency guidance issued by HHS (see Office for Civil Rights, U.S. Department of Health and Human Services, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons (Aug. 4, 2003), www.hhs.gov/ocr/civilrights/resources/specialtopics/lep/policyguidancedocument.html).

³Administration on Aging, U.S. Department of Health and Human Services, Minority Aging (Aug. 14, 2008), www.aoa.gov/AoARoot/Aging_Statistics/Minority_Aging/index.aspx ("Population Projections by Race and Hispanic Origin: Persons Aged 65 and over: 2000–2050"). Most of the underlying data for reports that we cite here are from the 2005–2007 American Community Survey conducted by the U.S. Census Bureau, www.factfinder.census.gov. Census Bureau racial and ethnic data categories have changed over time, and data are drawn from different periods. The information in this article is not presented to show precise conditions at any point in time.

⁴Administration on Aging, U.S. Department of Health and Human Services, A Statistical Profile of Hispanic Older Americans Aged 65+, www.aoa.gov/AoARoot/Aging_Statistics/Minority_Aging/Facts-on-Hispanic-Elderly-2008.aspx (last modified March 10, 2009).

⁵Administration on Aging, U.S. Department of Health and Human Services, A Statistical Profile of Asian Older Americans Aged 65 and Older, www.aoa.gov/AoARoot/Aging_Statistics/Minority_Aging/Facts-on-API-Elderly2008-plain_format.aspx (last modified on March 10, 2009); Administration on Aging, U.S. Department of Health and Human Services, A Statistical Profile of Black Older Americans Aged 65+, www.aoa.gov/AoARoot/Aging_Statistics/Minority_Aging/Facts-on-Black-Elderly2009-plain_format.aspx (last modified March 10, 2009).

⁶FEDERAL INTERAGENCY FORUM ON AGING-RELATED STATISTICS, 2008 OLDER AMERICANS: KEY INDICATORS OF WELL-BEING 82 (2008), www.agingstats.gov/agingstatsdotnet/Main_Site/Data/Data_2008.aspx (2006 data) [hereinafter KEY INDICATORS].

⁷2005–2007 American Community Survey, *supra* note 3 (2003 data).

⁸Henry J. Kaiser Family Foundation, Key Facts: Race, Ethnicity & Medical Care 6 (2007), www.kff.org/minorityhealth/upload/6069-02.pdf (based on U.S. Census Bureau's March 2006 Current Population Survey).

trast, only 38 percent of elderly whites have incomes below this level.⁹

Differences in savings and assets also are stark. In 2005 median net worth among older black households was estimated to be about \$38,000 compared to \$227,000 among older white households—a difference of more than 600 percent.¹⁰

Because they are poor, older women of color disproportionately are dual-eligible individuals, who qualify for both Medicare and Medicaid benefits.¹¹ Racial and ethnic minorities make up 45 percent of dual-eligible beneficiaries.¹² Women constitute 63 percent of dual-eligibles.¹³

B. More Likely to Be Living with Family

Close to one-third of older black, Hispanic, and Asian women live with relatives compared to only 14 percent of older white women.¹⁴ Older women of color also are significantly more likely to be living with grandchildren and having an impact on their lives. More than one-half of the grandchildren living with grandparents are of racial and ethnic minority backgrounds.¹⁵ In immigrant families the

more usual pattern is a parent-maintained household shared with both grandparents and their grandchildren.¹⁶ In African American families the grandparents are the ones more likely to be maintaining a home with grandchildren.¹⁷ Grandmothers raising grandchildren by themselves face the toughest economic challenges: 63 percent of their grandchildren live in poverty.¹⁸

C. More Likely to Speak a Language Other than English

More than five million seniors, almost 10 percent of persons 65 or older, speak a language other than English at home.¹⁹ More than 60 percent of Hispanic and Asian elders who speak a foreign language at home report that they do not speak English “very well.”²⁰

D. More Likely to Have Poor Health Indicators

Health indicators among racial and ethnic minority elders continue to trail those of their white counterparts. Markers such as influenza vaccinations and eye examinations show lower participa-

⁹*Id.*

¹⁰KEY INDICATORS, *supra* note 6, at 87 (2005 data).

¹¹For additional discussion of issues that dual-eligible individuals face, see Mary A. Ashkar et al., *Medicare Advantage: What's the Advantage If You've Got Medicaid, Too?*, 42 CLEARINGHOUSE REVIEW 232 (Sept.–Oct. 2008); Alfred Chiplin et al., *Dazed and Confused: Navigating the Abyss of the Medicare Act of 2003 for Low-Income Beneficiaries*, 38 *id.* 443 (Nov.–Dec. 2004).

¹²Section 8: Medicare Dually Eligible Population in 2003, [Centers for Medicare and Medicaid Services' Medicare Current Beneficiary Survey] 38 (2003), www.cms.hhs.gov/MCBS/Downloads/CNP_2003_dhsec8.pdf.

¹³*Id.* at 37.

¹⁴KEY INDICATORS, *supra* note 6, at 8 (2007 data). These figures do not include women living only with their spouses.

¹⁵2005–2007 American Community Survey, *supra* note 3, Subject Table No. S1001, www.factfinder.census.gov/servlet/STTable?_bm=y&-geo_id=01000US&-qr_name=ACS_2007_3YR_G00_S1001&-ds_name=ACS_2007_3YR_G00_&-lang=en&-redoLog=false&-format=&-CONTEXT=st (2005–2007 estimates).

¹⁶See Ken Bryson & Lynne M. Casper, U.S. Census Bureau, *Coresident Grandparents and Grandchildren* 4, 5 (1999), www.census.gov/prod/99pubs/p23-198.pdf. Data in this report include grandparents who are younger than 65 and are based on immigrant status rather than ethnicity.

¹⁷*Id.*

¹⁸*Id.* at 8.

¹⁹2005–2007 American Community Survey, *supra* note 3, Subject Table No. S1601, www.factfinder.census.gov/servlet/STTable?_bm=y&-geo_id=01000US&-qr_name=ACS_2007_3YR_G00_S1601&-ds_name=ACS_2007_3YR_G00_&-lang=en&-redoLog=false&-format=&-CONTEXT=st (2005–2007 estimates). Information on language spoken at home is not reported by gender. A good gateway for additional information related to limited-English-proficient populations is Limited English Proficiency: A Federal Interagency Website, www.lep.gov.

²⁰2005–2007 American Community Survey, *supra* note 19, Subject Table No. S1601.

tion by minority seniors.²¹ Black and Hispanic Medicare beneficiaries self-report poorer health compared to whites.²²

II. Meeting the Challenge: A Program-Specific Response

With poverty and health needs so concentrated among older women of color, benefit programs must overcome access barriers arising from language limitations and culture. What program changes would make the most impact on the lives of these women, and how can advocacy build on the strong family networks and community ties that many of these elders enjoy? What would good enforceable regulations addressing these questions look like?

Answering these questions becomes more concrete in the context of specific real-world benefit programs. Here we look at how the needs of older women of color play out in one such program, the delivery of personal care services under Medicaid.²³ These services can include such items as assistance in bathing, toileting, and repositioning; domestic and related services, such as meal preparation and laundry; accompanying participants to medical appointments; and protective supervision for individuals who would be a danger to themselves if left alone.

States offer personal care services as a Medicaid benefit

- as an optional benefit, known as personal care services, under their state plans;²⁴
- as a covered service under a Medicaid home- and community-based waiver program, also known as a 1915(c) waiver;²⁵ or
- as part of a Section 1115 demonstration project.²⁶

Many states offer personal care services through more than one program.²⁷ The operational details of the personal care services program vary widely among states.²⁸

In the traditional model—that is, non-self-directed delivery of personal care services—states evaluate the care needs of a participant, allocate time for specific tasks, and authorize hours and budget accordingly.²⁹ States also determine the duties of care providers, contract with agencies, set pay scales, and handle the details of payment.³⁰

As an alternative to the traditional model, for well over ten years states have experimented with versions of a self-directed care model in which participants have varying degrees of choice in hiring care-

²¹AGENCY FOR HEALTHCARE RESEARCH AND QUALITY, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, AHRQ PUB. NO. 08-0041, NATIONAL HEALTH CARE DISPARITIES REPORT 2007, at 212–15 (2008), www.ahrq.gov/qual/qdr07.htm#toc.

²²Section 2: Health Status in 2003, [Centers for Medicare and Medicaid Services' Medicare Current Beneficiary Survey] 13 (2003), www.cms.hhs.gov/MCBS/Downloads/CNP_2003_dhsec2.pdf.

²³Personal care services are within the definition of “medical assistance” in Medicaid (42 U.S.C. § 1396d(a)(24) (2009)).

²⁴*Id.* A state plan is the basic document in which a state describes the groups of participants that it will serve under its Medicaid program and the services that it will supply to those participants (see *id.* § 1396a(a)).

²⁵Section 1915(c) is codified at *id.* § 1396n(c).

²⁶Section 1115 is codified at *id.* § 1315. Section 1115 provides CMS with broad authority to waive many statutory requirements to allow states to undertake experimental, demonstration, or pilot projects for limited periods to test new ways of delivering benefits (*id.*).

²⁷As of 2006 thirty-three states provided the personal care services benefit under their state plans; every state except Arizona provided some services under a Section 1915(c) waiver (see Henry J. Kaiser Family Foundation, Medicaid Benefits: Online Database—Benefits by Service: Personal Care Services (Oct. 2006), <http://medicaidbenefits.kff.org/service.jsp?gr=off&nt=on&so=0&tg=0&yr=3&cat=1&sv=28>).

²⁸For a discussion of variances among states, see Laura L. Summer & Emily S. Ihara, AARP Public Policy Institute, The Medicaid Personal Care Services Benefit: Practices in States that Offer the Optional State Plan Benefit (2005), www.aarp.org/research/assistance/medicaid/2005_11_medicaid.html.

²⁹Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57854, 57861 (Oct. 3, 2008).

³⁰*Id.* In some cases, pay scales have been negotiated by states or counties with unions representing the workers (see *id.* at 57869).

givers, who could be family members.³¹ In some cases, under Section 1915(c) waivers, states offered a “cash and counseling” option whereby participants were given a budget to pay caregivers directly and sometimes were permitted to use a portion of their allocated funds for other items, such as accessibility ramps.³²

In 2006, as part of the Deficit Reduction Act of 2005, Congress authorized, but did not require, states to offer self-directed personal assistance service programs as an option under state plans.³³ The Deficit Reduction Act added to the Social Security Act a new Section 1915(j) that defines the self-directed personal assistance service option as one where, pursuant to a self-directed service plan and budget, participants may purchase personal assistance and related services and “hire, fire, supervise, and manage” their care providers.³⁴

In October 2008 CMS issued regulations implementing the Deficit Reduction Act provisions.³⁵ The regulations provide that, in the self-directed option, participants or their representatives determine the qualifications of providers, hire them, and set their compensation and duties.³⁶ States have the option of disbursing cash prospectively to those

participants who are assessed as capable of handling payments, so that the participant may directly pay caregivers and manage tax withholding and reporting.³⁷ Any state choosing to permit direct cash disbursements to participants also must give those participants the option of using a financial management entity to handle payments.³⁸

Because many states already have variants of self-direction in place and the program is optional, advocates do not expect the regulations to change state practice quickly or drastically.³⁹ Nevertheless, for those states that offer the self-directed care option, the regulations discussed below do contain explicit directives about program operation, particularly the type and level of support that states must offer to individuals enrolled in the program.

Of particular interest is the extent to which the regulations incorporate requirements of cultural competence and language access, accommodation to the personal preferences of the participant, and integration of community resources into care.⁴⁰ These new rules are among the most explicit to date in incorporating these themes into specific federal regulations. Legal advocates should consider how they can use these new provisions to

³¹For a comprehensive handbook for states on the operation of self-directed programs, see ROBERT WOOD JOHNSON FOUNDATION, DEVELOPING AND IMPLEMENTING SELF-DIRECTION PROGRAMS AND POLICIES: A HANDBOOK (2009), www.cashandcounseling.org/resources/pdf/cc-full.pdf.

³²For a discussion of the history of the “cash and counseling” experiments, see Cash & Counseling, www.cashandcounseling.org/about/index_html (last visited March 25, 2009).

³³Deficit Reduction Act of 2005, Pub. L. No. 109-171, 120 Stat. 4 (Feb. 8, 2006). States also may continue to offer self-directed plans under Section 1915(c) waivers and as part of a Section 115 demonstration project (73 Fed. Reg. at 57856).

³⁴Social Security Act, 42 U.S.C. § 1396n(j).

³⁵73 Fed. Reg. 57854.

³⁶42 C.F.R. § 441.468(e) (2009). The regulations throughout refer to the rights and duties of participants or their representatives. CMS emphasizes that using a representative to assist a participant in the exercise of self-direction is not inconsistent with the self-delivery model (see 73 Fed. Reg. at 57857). Thus, e.g., a participant with cognitive limitations could still be a candidate for self-direction if a representative were capable of handling details beyond the capacity of the participant herself.

³⁷42 C.F.R. § 441.454(a) (2009).

³⁸*Id.* § 441.454(c).

³⁹Also, the statute permits states to limit the number and categories of participants and does not require statewide availability (“statewideness”) of the self-directed personal assistance service option (42 U.S.C. § 1396n(j)(3) (2009)).

⁴⁰The regulations and the experiments that preceded them were primarily a response to advocacy by the disability community for more independence and control over the services that they receive (see 73 Fed. Reg. at 57855). Nevertheless, many of these provisions have the potential for as much or greater impact on the specific needs of racial and ethnic minority elders.

push for greater language access and cultural competence in the administration of the personal care services program. Advocates also should monitor how well these regulations succeed in meeting the needs of older women of color and their communities and whether they are an appropriate model for regulatory change in other programs.

III. Self-Directed Personal Care Services and the Needs of Older Women of Color

The regulations governing the self-directed option for personal care services have many elements that, if implemented fully, could be of particular benefit to older women of color. The comprehensive regulations on the self-directed option address all aspects, including qualifications to participate in the program, explaining options to beneficiaries, services offered, counseling and support, and quality assurance and improvement plan. Throughout the regulations the emphasis is on deference to the needs and desires of the participant.

A. Qualifying for Services

Before taking up the new regulations, we look at the challenges that older women of color face in qualifying for personal care services, whether or not they choose the self-directed option.

The initial step is an evaluation by a caseworker or other professional. This typically involves a home visit where the applicant discusses or demonstrates (or both) needs for assistance in activities of daily living and instrumental activities of daily living.

A shortage of bilingual caseworkers or interpreters can create serious problems of timely access to the personal care services program. Advocates report, for example, that, for nine months, one large diverse county in Northern California had no Spanish-speaking caseworker to handle personal care service evaluations; some Spanish-speaking seniors waited more than a year for assessment and enrollment.⁴¹

Even when language proficiency is not a barrier, cultural competence remains critical. Unlike other programs where only financial qualifications are at issue or where a report from one's trusted medical provider may suffice to qualify for a Medicaid service, the evaluation for personal care service programs frequently involves a stranger entering the home and assessing intimate and potentially embarrassing personal needs.⁴² Without sensitivity to the cultural norms of the beneficiary, valuable information about the true level of need can easily be overlooked or lost.⁴³

Advocates may need to intervene through formal or informal complaints when counties fail to evaluate individual clients timely or fail to use appropriate interpreter services; advocates may need to push for systemic improvements in hiring bilingual caseworkers and qualified interpreters and for cultural competency training for all evaluators.⁴⁴

B. Explaining Options to Beneficiaries

The new regulations do not change the rules for evaluating whether an individual qualifies for the personal care services program. They do, however, require that at the evaluation or sometime

⁴¹Telephone Interview with Crystal Padilla, Advocate, and Daniel Brzovic, Associate Managing Attorney, Disability Rights California, in Oakland, Cal. (April 8, 2009).

⁴²In a minority of states, physicians order care. Other states employ individuals ranging from nurse practitioners to county caseworkers to make assessments (see Summer & Ihara, *supra* note 28, at 12).

⁴³E.g., due to the cultural norm of shyness, a Chinese elder may be reluctant to talk to an outsider about health and psychosocial problems (see Kim Wright et al., University of North Carolina at Charlotte, Are You Culturally Aware?, <http://personal.uncc.edu/macurran/2002/webproject/HOME.HTM> (last visited April 7, 2009)).

⁴⁴Many resources for cultural competency training are available. A good collection of materials can be found at Office of Minority Health, U.S. Department of Health and Human Services, www.omhrc.gov/templates/browse.aspx?lvl=1&lvlid=3 (last visited May 17, 2009); Health Resources and Services Administration, U.S. Department of Health and Human Services, Cultural Competence Resources for Health Care Providers, www.hrsa.gov/culturalcompetence (last updated April 27, 2009); National Center for Cultural Competence, *supra* note 1.

in the enrollment process states offering the option of self-directed care must assess the individual's "needs, strengths, and preferences" for self-directed care and inform the individual about the availability of the option, the alternative of receiving services through the more traditional model, and the rights and risks of both.⁴⁵ Information on feasible alternatives "must be communicated to the individual in a manner and language understandable by the individual."⁴⁶ This requirement, particularly given the complexities involved with self-directed care, demands cultural competence as well as communication in the beneficiary's preferred language.

C. Services Offered

Several aspects of the new regulations governing the creation and implementation of a self-directed service plan, if properly implemented, would be of particular benefit to older women of color. For example:

- The state must allow the participant or representative the opportunity to involve family, friends, and professionals as desired in the development and implementation of a service plan.⁴⁷
- The service plan "builds upon the participant's capacity to engage in activities that promote community life and respects the participant's preferences, choices, and abilities."⁴⁸

- The participant must, at a minimum, have authority to recruit, hire, and fire providers; set their pay; determine their duties and schedule, train, and evaluate them; and review their invoices.⁴⁹ The regulations do not impose an age limit on providers.⁵⁰
- Although state "support brokers" provide counseling, the participant, not the state, determines the qualifications of providers to be hired. Participants retain the right to train their providers and to require them to perform tasks "in a manner that comports with the participant's personal, cultural, and/or religious preferences."⁵¹
- Participants have the right to send their providers to state-offered training sessions that the participants believe are necessary to meet additional qualifications "required or desired" by the participants.⁵²
- At a state's option, participants may be permitted to hire family members, including those who are "legally liable" for care of the participants, for example, their spouses.⁵³
- Although states may impose requirements such as criminal background checks, the participant decides whether a criminal record should be disqualifying.⁵⁴

⁴⁵42 C.F.R. § 441.466(a) (2009).

⁴⁶*Id.* § 441.464(c). Information must include at least elements of self-direction versus non-self-directed services, responsibilities, and liabilities; the choice to receive services through a waiver program if applicable; and the option, if applicable, to manage one's own budget (*id.*).

⁴⁷*Id.* § 441.468(c)(2).

⁴⁸*Id.* § 441.450(c). This acknowledgment of the potential of participants to contribute to community life also is found in the statute (42 U.S.C. § 1396n(j)(5)(c)(i) (2009)).

⁴⁹42 C.F.R. § 441.468(e) (2009).

⁵⁰See 73 Fed. Reg. at 57873.

⁵¹42 C.F.R. § 441.478 (2009).

⁵²*Id.* § 441.478(b).

⁵³*Id.* § 441.478(a). For the definition of "legally liable relatives," see *id.* § 441.450(c). If the participant has a personal representative, that representative may not provide paid services under the self-directed option (*id.* § 441.480(b)). Nor may the participant pay for services of a personal care provider who owns, operates, or controls the home or property where the participant lives unless the provider is related to the participant by blood or marriage (*id.* § 441.460(a)). Thus individuals living in an assisted-living facility that provides care services may not avail themselves of the option of self-directed personal assistance services of that facility.

⁵⁴See 73 Fed. Reg. at 57873.

- State policies must ensure that the planning process for developing the service plan is “timely.”⁵⁵
- The planning process must be “person-centered.”⁵⁶
- States must ensure that the “the qualifications of the individuals who are responsible for service plan development reflect the nature of the program’s target population(s).”⁵⁷

The program design of the self-directed model necessarily involves risk (CMS refers to the concept of “dignity of risk”), and advocates working with particular cultural communities need to be alert to community norms that might increase those risks.⁵⁸ CMS encourages states to enter into “risk agreements” with participants; the agreements are to identify the risks that the participants are willing to assume, the responsibilities of the participants and others to mitigate those risks, and the conditions under which the agreement would be terminated—for example, participants would be involuntarily disenrolled from the self-directed option.⁵⁹ Advocates need to monitor such agreements for fairness because CMS does not mandate a specific appeals process for involuntary disenrollment from the self-directed option. (Note, however, that involuntary disenrollment from the self-directed option does not affect

rights to receive personal care services under the traditional model.)⁶⁰

Despite these caveats, the flexibility of the program rules for the self-directed option can be advantageous for many older women of color. Participants may hire caregivers in their own community, including family members, who speak their language and share their cultural norms. Participants may hire caregivers whom they deem competent even if those individuals do not, for example, speak English well or have particular training certifications. Caregivers may be required to provide services in a manner comporting with the preferences of the participant. All of these requirements offer opportunities for genuinely community-based care that is respectful of the elder and strengthens the elder’s ties to family and community.

Moreover, poor older women of color, who disproportionately live with and are cared for by their family, may pay family providers under the program. In some cases, older women of color may themselves be caregivers, either of spouses or family members who are older still or are disabled.⁶¹ Bringing in the extra income to a household in poverty can decrease financial and emotional stress. This extra income can be particularly beneficial when the caregiver is a spouse because income as a caregiver does not affect

⁵⁵42 C.F.R. § 441.468(c)(3) (2009). The *Federal Register* notice does not define or discuss what is “timely.”

⁵⁶*Id.* §§ 441.464(d), 441.468(b). CMS declined to define “person-centered” in the regulations. In its commentary, however, CMS listed eight characteristics of a person-centered model, among them being such elements as services and supports based on the preferences and strengths of the person, inclusion of the person in planning, and meaningful choices for the person (see 73 Fed. Reg. at 57861).

⁵⁷42 C.F.R. § 441.468(c)(6) (2009). CMS described these qualifications as knowledge about participants who will be self-directing their personal care services and skill in person-centered planning (73 Fed. Reg. at 57869). In our view, cultural ties to the communities where participants live, language skills, and a familiarity with available community-based resources also would be key qualifications for serving a target population that includes ethnic and cultural minority elders.

⁵⁸See 73 Fed. Reg. at 57858. The most commonly identified risk in self-direction is harm to the participant because a care provider does not show up; among other risks are the potential for exploitation by relatives or choosing a provider who lacks necessary skills (see *id.* at 57859). For a discussion of management of risks, see ROBERT WOOD JOHNSON FOUNDATION, *supra* note 31, at 9-8 to 9-12.

⁵⁹73 Fed. Reg. at 57863.

⁶⁰See *id.* at 57861–62.

⁶¹Among older men 73 percent live with their spouses (see Administration on Aging, U.S. Department of Health and Human Services, *A Profile of Older Americans: 2008*, www.aoa.gov/AoARoot/Aging_Statistics/Profile/2008/5.aspx (last modified March 19, 2009)).

Supplemental Security Income eligibility for either the participant or the caregiver spouse.⁶²

The requirement that state-offered training opportunities be available to caregivers selected by participants is another lever for language access advocacy. For this requirement to be meaningful for limited-English-proficient caregivers, training materials must be available in multiple languages, and training sessions must accommodate limited-English-proficient care providers.

D. Counseling and Support

To take into account the risks attendant to a self-directed model, CMS regulations specify requirements for ongoing counseling of participants. States must assign a case manager or “support broker” to advise a participant about the risks and requirements of self-directed plans, explain that the participant has the option to disenroll at any time and return to a more traditional model, and continue to monitor a participant’s self-direction of services.⁶³ The state must implement a support system that provides appropriate information, counseling, and training to the participant and must communicate the information “in a manner and language understandable by

the participant.”⁶⁴ Support brokers function as agents of the participants and take direction from the participants about what counseling, training, or assistance is needed or desired.⁶⁵

If the participant is handling payments directly, counseling must include a financial element.⁶⁶ A financial management entity must monitor a participant’s handling of finances and flag problems that the participant has in managing the care budget.⁶⁷ The entity also must be available to handle payments to caregivers if the participant does not wish to or if the participant is determined, after counseling, to be unable to do so.⁶⁸

The counseling portion of the regulation specifically requires that the participant must be given information on “an advocate or advocacy systems” available in the state and how the participant can access the advocate.⁶⁹ This requirement can lead to improved communication and cooperation between advocates and government agencies operating personal assistance service programs.⁷⁰ It also raises for advocacy organizations the question of how well equipped they are to meet their own obligations to serve their racial and ethnic minority clients and what more they should be doing to improve their own cultural competence.⁷¹

⁶²If both spouses qualify for Supplemental Security Income, payment to a spousal caregiver would not count as income because the payment is cash assistance under a government program whose purpose is to provide medical care or medical services (see 20 C.F.R. § 416.1103(a)(3) (2009)). The payment could also qualify under the social services exception (*id.* § 416.1103(b)(1)). If the spousal caregiver is not disabled and is under 65, the relevant provision states that the income of an ineligible spouse should not be deemed if it is paid under a government program to provide the individual with “chore, attendant or homemaker service” (*id.* § 416.1161(a)(16)). When counseling participants who want to employ family members, advocates should consider the implications for any other relevant income-based benefits.

⁶³42 C.F.R. § 441.464 (2009).

⁶⁴*Id.* § 464(d)(2).

⁶⁵*Id.* § 441.450.

⁶⁶*Id.* § 441.464(d)(2).

⁶⁷*Id.* § 441.464(a).

⁶⁸*Id.* § 441.454(d).

⁶⁹*Id.* § 441.464(d).

⁷⁰E.g., advocates could work with agencies on consumer materials explaining the rights of program participants and available legal resources or develop consultative mechanisms for periodic review of program efforts to serve minority populations.

⁷¹For a discussion of the obligations of attorneys in legal services to limited-English-proficient clients, see Katharine Hsiao & Gerald McIntyre, *What You Need to Know About Advocacy for Limited-English-Proficient Elders*, 42 CLEARINGHOUSE REVIEW 301 (Sept.–Oct. 2008). The National Senior Citizens Law Center has an advocates’ checklist, Best Practices for Reaching Out and Serving Limited English Proficient (LEP) Clients (n.d.), www.nslc.org/areas/medicare-part-d/advocate.

E. Quality Assurance and Improvement Plan

The new regulations require states to have a quality assurance and improvement plan that tracks and responds to critical incidents and has unspecified “system performance measures, outcome measures, and satisfaction measures.”⁷² Also required from the state are a quantitative (i.e., number served, amounts spent, etc.) annual report to CMS and a three-year program evaluation, the content of which has not yet been determined.⁷³ Neither the regulations nor the CMS commentary accompanying their release mentions language access or cultural competence as areas that should be covered in performance measurements.

Advocates should consider working with state and local agencies to ensure that reporting and evaluation systems have specific data on the experience of racial and ethnic minority participants and track such items as the impact of limited-English-proficient status on timeliness of participant evaluations and assessments; the extent to which service plans reflect the cultural, religious, and personal preferences of the participant; and the accessibility of grievance and complaint mechanisms to limited-English-proficient individuals. The reporting system should be transparent with composite data available to participants, advocates, and the public; with data broken out by race and ethnic minority status so that patterns could be spotted; and with periodic reports on how deficiencies are being handled. Without effective monitoring and accountability, gauging whether program mandates are being fulfilled is impossible.

IV. Leveraging Regulations

Older women of color are a growing segment of the U.S. population. They are

disproportionately poor, disproportionately dual-eligible individuals (receiving both Medicaid and Medicare benefits), and more likely than their white counterparts to have poor health indicators. Many are limited-English-proficient. Older women of color are more likely to live with family members and in multi-generational households than their white counterparts.

Access to benefit programs that serve the needs of older women of color in appropriate languages and in a culturally competent manner is a key need for this population. Getting services from within their own cultural community not only allows older women of color to age with dignity but also strengthens the fabric of the community in which they live. Released in October 2008, regulations concerning the self-directed option for delivery of Medicaid personal care services have provisions that, if fully implemented, would tackle the issues of language, cultural competence, and community-based services and allow use of family members as paid caregivers.

Advocates should consider how these regulations affect the delivery of the personal care service benefit to older women of color in their states and how to use the regulations as a lever to gain program improvements. The regulations also provide an interesting model of how to mandate cultural competence and could be a useful starting point for crafting regulations governing other programs. As advocates work to incorporate cultural competence and community-centered approaches into regulations governing other programs, they may want to monitor how well these regulations succeed in bringing about real improvements in how racial and ethnic minority elders receive services.

COMMENTS?

We invite you to fill out the comment form at <http://tinyurl.com/MayJuneSurvey>. Thank you.

—The Editors

⁷²42 C.F.R. § 441.474 (2009).

⁷³*Id.* § 441.464(e), (f).

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