

The 2006 Report to the Secretary: Rural Health and Human Service Issues

The NACRHHS

**The National Advisory
Committee on Rural Health and
Human Services**

January 2006

Acknowledgements

The *2006 Report to the Secretary* is the culmination of a year of collective effort by the National Advisory Committee on Rural Health and Human Services. I would like to thank each of the Committee members for their hard work, but I would like to give special attention to the chairs of the subcommittees of each of the three chapters: Sue Birch, Family Caregiver Support of the Rural Elderly; Michael Meit, Health Information Technology in Rural Areas; and Tom Ricketts, Access to Pharmaceuticals and Pharmacy Services in Rural Areas. I would also like to mention the hard work of McKing Consulting Corporation's Jake Culp and Sahi Rafiullah, who drafted key sections of the report, and Jeff Human, Jennifer Roberts and Felicia Pratt, who managed the logistics for each of the Committee meetings. Deanna Durrett, Anjali Garg and Phuong Luu, Truman Fellows with the Office of Rural Health Policy, provided research support and assistance in drafting key sections of the final report. Finally, I would like to thank Beth Blevins for her work in the editing and layout of the report.

The Committee relied on a number of important data sources for this report. The American Hospital Association and the Office of the National Coordinator for Health Information Technology provided data for the chapter on Health Information Technology in Rural Communities. The Rural Assistance Center, American Pharmacists Association and the American Society of Health Systems Pharmacists provided data for the Access to Pharmaceuticals and Pharmacy Services chapter. Rick Greene from the U.S. Administration on Aging, Kathleen Kelly from the Family Caregivers Alliance, and Charlene Harrington and Martin Kitchner from the University of California, San Francisco provided data for the chapter on Family Caregiver Support of the Rural Elderly.

The contributions of Federal staff also improved this report to a large extent. They include Marcia Brand, Tom Morris, Jennifer Riggle, Michele Pray-Gibson, Karen Stewart, Emily Cook and Keith Midberry in the Health Resources and Services Administration's (HRSA) Office of Rural Health Policy; Nikki Bratcher-Bowman in the Office of Intergovernmental Affairs at the Department of Health and Human Services; Dennis Dudley of the Administration on Aging; and Jimmy Mitchell from the HRSA Office of Pharmacy Affairs.

The Committee also benefited from the hospitality and rich information provided by various individuals involved with the Committee's two site visits over the past year. In June of 2005, the Committee visited Johnson City, Tennessee. The organizations representing the region, which included Johnson County Health Center, Wilson Pharmacy and Mountain Empire Older Citizens, Inc., all helped to inform the report you see here. We heard from several key speakers including Paul Stanton and Ron Franks from East Tennessee State University, Howard Chapman from Southwest Virginia Community Health Systems, Lisa Jenkins from CareSpark, Nancy Peace from the Tennessee Commission on Aging and Disabilities, Kathy Whitaker from First Tennessee Development District Area Agency on Aging and Paul Moore, an independent pharmacist from Atoka, Oklahoma. Special thanks go to Bruce Behringer and Joellen Edwards for coordinating and hosting this meeting. In September of 2005, the Committee visited Wilson, Wyoming and benefited greatly from the work of the individuals in the region at the St. John's Medical Center, St. John's Medical Center Foundation and the Star Valley Senior Citizens Center. We appreciated the information presented by Brent Sherard, Bev Morrow and Roxanne Homar from the Wyoming Department of Health, Robert Kelley from the University of Wyoming College of Health Sciences, Michael Stelmach from John Snow Inc., Kris Urbanek from the Mountain-Pacific Quality Health Organization and Gary Shatto from Frontier Drug. Thank you to Michael Enright, for coordinating and hosting the fall meeting. Special thanks should also go to Lynn Weidel and Penny Hunt for their assistance in planning the Wyoming meeting.

Finally, the Committee would like to recognize the passing of an important leader in the field of rural health. James Bernstein's work on improving the health of rural Americans through the creation of the first State Office of Rural Health in North Carolina and his commitment to training the next generation of rural health leaders has been felt throughout the United States. The Committee hopes to honor Bernstein's legacy continually through its work in advocating for improved rural health and human services.

Sincerely,

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About the Committee

The National Advisory Committee on Rural Health and Human Services (NACRHHS) is a 21-member citizens' panel of nationally recognized rural health experts that provides recommendations on rural issues to the Secretary of the Department of Health and Human Services. The Committee, chaired by former South Carolina Governor David Beasley, was chartered in 1987 to advise the Secretary of Health and Human Services on ways to address health and human service problems in rural America.

The 21-member Committee's private and public-sector members reflect wide-ranging, firsthand experience with rural issues—in medicine, nursing, administration, finance, law, research, business, public health, aging, welfare and human service issues.

Each year, the Committee chooses key health and human service issues affecting rural communities to highlight. Background documents are then prepared for the Committee by both staff and contractors to help inform members on the issues. The Committee then produces a report with recommendations on those issues for the Secretary by the end of the year. The Committee also sends letters to the Secretary after each meeting. The letters serve as a vehicle for the Committee to raise other issues with the Secretary separate and apart from the report process.

The Committee meets three times a year. The first meeting is held in early winter in Washington. The Committee then meets twice in the field (in June and September). The Washington meeting usually coincides with the opening of a Congressional session and serves as a starting point for setting the Committee's agenda for the coming year. The field visits include ongoing work on the yearly topics with some time devoted to site visits and presentations by the host community.

The Committee is staffed by the Office of Rural Health Policy, which is located within the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Additional staff support is provided by the Administration on Children and Families, the Administration on Aging and the Office of the Secretary's Office of Intergovernmental Affairs.

Contents

Executive Summary	1
Introduction	5
References	7
Access to Pharmaceuticals and Pharmacy Services in Rural Areas	9
Recommendations	21
References	24
Health Information Technology in Rural Areas	27
Recommendations	39
References	40
Family Caregiver Support of the Rural Elderly	43
Recommendations	60
References	62
Acronyms Used	65

Executive Summary

This is the *2006 Report to the Secretary of Health and Human Services* by the National Advisory Committee on Rural Health and Human Services. This year's report examines three key topics: access to pharmaceuticals and pharmacy services in rural areas; health information technology in rural areas; and family caregiver support of the rural elderly. All are pertinent and timely topics that the Committee chose during its March 2005 meeting.

Access to Pharmaceuticals and Pharmacy Services in Rural Areas

Access to pharmaceuticals and pharmacy services is an increasing challenge for rural communities. As prescription medications increase in usage and cost, problems with affordability and access continue to result. This issue is particularly important for rural areas because of their particular socio-economic, demographic and health status challenges. This chapter focuses on the evolving prescription drug marketplace alongside obstacles dealing with financial access and workforce availability.

Financial access to pharmaceuticals is a major issue in rural areas where a higher percentage of families lack health insurance and there are fewer employment opportunities that include insurance coverage for prescriptions. Spending on prescription drugs nationwide increased 16 percent from 2000 to 2001 compared to a 9 percent increase in physician and clinical services and an 8 percent increase in hospital costs. The high cost of pharmaceuticals is especially difficult for rural communities that have millions of low-income workers and a disproportionate share of rural residents enrolled in Medicare, Medicaid or the State Children's Health Insurance Program.

Both rural consumers and rural pharmacists are dealing with the financial issues of prescription drugs. In-

dependent pharmacies are the most common type of pharmacy in rural areas, yet they are increasingly receiving competition from mail-order companies and retail chains. Given their small size and thin profit margins, many independent pharmacies are facing the possibility of impending closure.

In addition, the issue of workforce availability of pharmacists and other qualified health care professionals who can dispense drugs in rural areas is a crucial factor in the access to pharmaceuticals and pharmacy services discussion. Only 12 percent of pharmacists nationwide practice in rural areas and rural areas have fewer pharmacists proportionally than urban areas. Rural communities are also dealing with an aging population of pharmacists whose impending retirement is threatened by an insufficient number of younger pharmacists practicing in rural areas.

Besides financial accessibility and workforce availability, the chapter also discusses the possible impacts that implementation of the Medicare Modernization Act (MMA) might have on rural residents and rural independent pharmacies. Clearly, the creation of a drug plan for Medicare beneficiaries will have a tremendous benefit to seniors and, particularly, to rural seniors who are less likely to have had coverage through a third-party or supplemental provider. Still, with any dramatic change in the Medicare program, there are growing pains and unintended consequences. Through testimonies and site visits, the Committee discovered concerns among rural seniors and rural policy experts about the impact of the new Medicare drug benefit. For example, the Committee heard from seniors that signing up for the new benefit is confusing given the complex choices among competing plans that offer different pre-approval requirements, different formularies for covered drugs, different access points and other variables. Moreover, some rural experts are worried that access to local pharmacies may be at risk in rural communities if the prescription drug plans rely too heavily on mail-order companies to distribute the drugs or if rural

beneficiaries are forced to use mail-order services because of potentially lower costs in co-pays. In that situation, there is concern that the MMA could indirectly contribute to the loss of business for independent pharmacies as well as lead to decreased consumer knowledge of prescription drug use.

In the Committee's examination of the issues surrounding access to pharmaceuticals and pharmacy services in rural areas, the Committee makes several recommendations to the Secretary, including:

- The Secretary should seek authorization to allow pharmacists to be eligible for the National Health Service Corps, and to provide the funding for the National Health Service Corps to provide them with scholarships and loan repayments options.
- The Secretary should support research on the potential risks of pharmacy closures in rural communities using Evidence-based Practice Centers supported by the Agency for Healthcare Research and Quality.
- The Secretary should support an annual study for the next five years that examines the impact of the Medicare Modernization Act on rural pharmacies and rural residents' access to pharmaceuticals and pharmacy services.

Health Information Technology in Rural Areas

In April of 2004, President George W. Bush issued an Executive Order calling for most Americans to be connected to an electronic health record within ten years. In order to implement this ambitious plan, the Office of the National Coordinator on Health Information Technology (ONCHIT) was created under the Department of Health and Human Services (HHS), and HHS Secretary Mike Leavitt has made this one of his key priorities. Before this Executive Order, concerns over health information technology (HIT) needs were voiced throughout the United States in both rural and urban discussions about health care quality, medical errors, access to care and population health. Discussions on HIT have ranged from technology such as bar coding and computerized provider order entry to the provi-

sion of direct clinical care via telemedicine and telehealth technologies.

It is evident that HIT presents a number of opportunities for the health of rural America. HIT can help disparate rural providers from across the spectrum of care better coordinate services for their patients. It also has the ability to help rural communities improve public health through disease surveillance and targeted health education. A recent Institute of Medicine report asserts that investing in HIT in rural America will help achieve the six quality aims set forth in its original *Crossing the Quality Chasm* report: make health care safer, more effective, patient-centered, timely, efficient and equitable.

Despite the discourse surrounding the myriad of HIT options, the focus of the President and ONCHIT has been on electronic health records (EHRs). What makes this national issue especially pertinent to rural communities is that EHR adoption is not equal across health care providers. Rural America cannot afford to be left behind in the adoption of this technology. Many rural providers lack the resources of their urban and suburban counterparts, which makes any investment in EHRs a potential risk given the limited capital for HIT investment, rapid changes in technology and the dearth of national technical standards.

To aid in HIT adoption, ONCHIT has produced a Framework for Strategic Action with the following four goals for the implementation of HIT, and specifically, EHRs. These goals are:

- Inform clinicians
- Interconnect clinicians
- Personalize care
- Improve population health

This chapter examines each of the four goals as well as the National Coordinator's proposed phases of implementation within each of these goals from a rural perspective. The general conclusion of this chapter is that rural providers must successfully achieve adoption of HIT at the start of the national movement. The limited infrastructure and availability of capital in rural areas makes the planning and adoption an even more critical and immediate step for rural America. The Committee

specifically highlights challenges in rural infrastructure, workforce and resources, and also emphasizes that rural health systems are not just smaller versions of urban and suburban systems—HIT adoption in rural communities may follow different phases of implementation than other systems. This chapter attempts to explain the adoption gap and proposes recommendations on how to ensure that rural America is not left behind as the HIT agenda moves forward.

The chapter draws from a wide variety of literature as well as limited data sources and conversations with Federal, State and local stakeholders. Through its findings, the Committee makes several recommendations, including:

- The Secretary should work with the Congress and the Federal Communications Commission to allow the use of Universal Service Funds for rural health care providers to build greater infrastructure for broadband access in rural communities.
- The Secretary should encourage groups like the American Health Information Community to consult with the Federal Office of Rural Health Policy, HHS Office of Intergovernmental Affairs and other key national rural health organizations about the impacts of their decision-making on rural communities.
- The Secretary should devote funding resources to ensure that technical assistance is available for rural communities after the final release and dissemination of the VistA-Office EHR software.

Family Caregiver Support of the Rural Elderly

Families—not nursing homes, social service agencies or other formal programs—provide the most long-term care to older persons with disabilities. The Administration on Aging (AoA) reported in 1994 that there are 44 million family caregivers in the United States and 34 million of them care for someone 50 years old or older. The majority of family caregivers are female, comprising 56 percent of the total number.

Two-thirds of all family caregivers also work out-

side the home. Some 62 percent of caregivers have had to make some kind of adjustment in their work life, such as reducing hours, taking early retirement, going from full-time to part-time work or taking unpaid leave. The American Geriatrics Society reports that one in five family caregivers will quit his or her job to become a full-time (and unpaid) caregiver.

The issue of family caregiver support may be more pressing in rural areas where there is a higher proportion of the elderly. On the whole, the rural elderly have less access to skilled nursing and other long-term care services compared to their urban and suburban counterparts. In fact, access to quality health services, in general, was identified as the top rural health priority among State and local health care leaders. Without these formal services available, the rural elderly rely even more on family and friends for assistance.

This chapter focuses on the challenges of rural family caregivers, who are characteristically more independent and, therefore, more hesitant to seek help and more resistant to using formal services than their urban and suburban counterparts. In its site visits, the Committee found that rural family caregivers are often geographically isolated and hence lack the opportunity to learn of available services from the limited service providers that do serve rural communities. Isolation, resentment, guilt and anger plague the caregiver, in addition to missed work and other financial difficulties. Research shows that informal caregivers suffer from high levels of stress, burnout and insomnia, and are more likely to use psychotropic drugs. It is estimated that 20 percent of family caregivers suffer from depression, which is twice the rate of the general population.

Utilization of caregiver support services can be expanded through increased outreach and education to diminish the stigma related to these services. One factor that limits adequate family caregiver support for rural areas is fragmentation and a resulting lack of coordination among health and human services programs in rural areas, within Federal, State and local levels. Caregiving is an ongoing, long-term concern. Informal caregiving is the backbone of the American long-term care system, where the value of the services provided by informal caregivers is estimated to be \$257 billion annually, two times the amount currently spent

on home care and nursing home care. Significant benefits to individuals and society can be accrued by offering assistance to caregivers, especially in the first weeks of caregiving.

Given the increased need for more resources, more education and outreach, the Committee makes several recommendations to the Secretary, including:

- The Secretary should encourage better assessment of rural caregiver needs as part of the National Family Caregiver Support Program (NFCSP).
- The Secretary should create a prominent, national social marketing campaign on rural caregiving.
- The Secretary should establish a research grant program to study the rural application and impact of the five required NFCSP service areas.
- The Secretary should lower the match requirement for the Title III E program from 25 percent to 15 percent, thus aligning it with the match required of other AoA programs.

Introduction

The *2006 Report to the Secretary from the National Advisory Committee on Rural Health and Human Services* is the culmination of research and work by the Committee over the past year. The 21-member Committee, comprised of distinguished rural health and human service experts from across the nation, gathered in Washington, D.C. in March 2005 to begin work on the *2006 Report*. Each year, the Committee seeks to identify timely rural health and human service topics for its report. This year's topics are access to pharmaceuticals and pharmacy services in rural areas; health information technology in rural areas; and family caregiver support of the rural elderly.

During the March 2005 meeting, a cadre of rural health experts testified before the Committee to inform them about the issues relevant to the three selected topics. Rebecca Slifkin of the Rural Health Research Center at the University of North Carolina at Chapel Hill and Jimmy Mitchell of the HRSA Office of Pharmacy Affairs presented information on pharmacy issues facing rural areas. Kelly Cronin of the HHS Office of the National Coordinator for Health Information Technology and Helen Burstin of the HHS Agency for Healthcare Research and Quality met with the Committee on issues related to health information technology. Rick Greene of the HHS Administration on Aging testified before the Committee on the National Family Caregiver Support Act and other issues topical to family caregiver support. Greene was joined by Donna Butts of Generations United.

Following the March 2005 meeting, the Committee's chair, David Beasley, identified three Committee members to serve as chair of each of the subcommittees. Thomas Ricketts of North Carolina chaired the Access to Pharmaceuticals and Pharmacy Services Subcommittee. Michael Meit of Pennsylvania chaired the Health Information Technology Subcommittee. Finally, Sue Birch of Colorado chaired the Family Caregiver Support of the Rural Elderly Subcommittee.

Armed with information from the testimonies, the

Committee then conducted two field meetings to gather more information on these issues at the community level. The field meetings and site visits by the subcommittees took place in Johnson City, Tennessee and Wilson, Wyoming. The Tennessee meeting offered the Committee a perspective on the three issues in the context of the rural underserved in the Appalachian region. The Wyoming meeting afforded the Committee the opportunity to examine the three topics in the context of isolated rural frontier areas.

Undertaking a rural analysis of these issues was not without its challenges. The issue of access to pharmaceuticals and pharmacy services is extremely broad, given that there are multiple sub-issues to consider and weigh in on. While the issue is a challenge for both urban and rural areas, there are specific dimensions and implications that apply more to rural communities. As a result, this may have been the most challenging issue taken on by the Committee in recent years. In the case of the family caregiver support of the rural elderly and health information technology topics, the Committee faced the added burden of a lack of rural-specific data that would have better quantified the rural aspects of both issues. The challenge of finding rural-specific data is an ongoing concern for the Committee. While HHS supports and conducts a great deal of research each year, it does not often analyze the data by rural and urban demographics. This is an unfortunate opportunity loss for the Secretary. Having data separated between rural and urban areas would allow the Secretary to better understand the rural impacts of particular health and human service issues, and to identify how certain HHS programs can be utilized to address those problems.

Despite these hurdles, the Committee did its best to examine any relevant research studies, to use existing data sources, as appropriate, and to develop proxy measures that help to quantify rural concerns. In addition, the Committee drew on the experience of all of its members and of the many experts both nationally and in the field to inform the report.

As in years past, the Committee sought to select topics that are timely within the national health care debate though still crucial within the context of rural health. The three topics in this year's report are currently being examined by HHS and other national policymakers. With the *2006 Report*, the Committee hopes to contribute to the national discussion of these issues and to ensure that rural concerns are taken into account, particularly as they relate to HHS activities in these areas.

In the report, the Committee provides the current national context for each chapter's topic in the section, "Why the Committee Chose This Topic." Then, the discussion moves from the national level onto rural-specific issues in the chapter section, "What Is Known About (the Topic)." Next, the Committee highlights the work of HHS and other governmental agencies in "Current HHS and Governmental Role." The Committee then offers a "Conclusion" and its "Recommendations" for the Secretary on how HHS can address some of the obstacles and challenges related to the topic.

The high cost of medications has brought the issue of access to pharmaceuticals and pharmacy services to the forefront of the national debate. Central to the discussion is the tremendous increase in medications to treat an ever-widening array of diseases and conditions. These trends provide health professionals and the patients they care for expanded opportunities to treat disease, save lives and manage chronic conditions. The potential to improve quality of health care, however, is undermined by serious issues concerning the steep rise in medication costs and lack of pharmacy access for many Americans. The elderly are at the center of the medication issue because they have a disproportionate share of prescription drugs utilization.¹ Thus, the elderly as a group are most vulnerable to the challenges of access to pharmaceuticals and pharmacy services. The case is keener in rural communities where there is a higher proportion of the elderly, a higher rate of the uninsured and a higher rate of poverty.² These combined factors signify the need to highlight rural areas' obstacles in obtaining adequate access to pharmaceuticals and pharmacy services.

Alongside the prominent discussion about pharmaceuticals, health information technology has garnered a tremendous amount of attention, and appropriately

so. Health information technology provides an effective means to improve quality of care. This issue is especially important for rural communities since health information technology has the ability to streamline the process of communication within and between health care facilities. Though urgently needed, the Committee discovered that rural areas do not currently possess the same level of expertise, funding and infrastructure to adopt and implement health information technology, as do their urban and suburban counterparts.

Finally, the pending move of a significant portion of the baby boom generation into retirement is already creating service challenges for many Americans. Within the next 30 years, the number of people eligible for retirement is expected to double.³ This issue provides timeliness and pertinence to the Committee's choice to address the family caregiver support topic. Already many families are filling the role of caregiver for elderly relatives and friends. In some cases, it is children caring for elderly parents, while in others it is siblings caring for siblings or spouses for spouses. Although these situations might be more ideal than nursing homes or assisted living, the strain on the caregivers is evident and the challenges are further complicated in rural areas due to a higher proportion of the elderly, a higher burden of chronic diseases among rural residents and a lack of infrastructure to support the caregivers.

No issue exists solely on its own. This is especially valid for the three topics chosen this year. Each of the topics has mutually reinforcing impacts, and though they are treated as separate chapters within the report, the need to recognize their interdependency must be noted.

What links these three topics can be explained through one general example. More than ever, Americans are utilizing medications. In a California survey conducted by the U.S. House of Representative's Committee on Government Reform, the study found that 91 percent of the elderly were taking some form of medication and, on average, each elderly person was taking four pills a day.⁴ Given the fact that rural areas have a disproportionate share of the elderly, the potential burden of the family caregiving role there is greater. Like other caregivers, rural caregivers have to juggle keeping abreast of all the possible drug side effects and

drug-drug interactions along with the other responsibilities of caregiving. However, rural areas face a lack of health information technology to facilitate a streamlined process of communication among disparate health care providers. In addition, health information technology such as bar coding, software programming to detect adverse drug reactions, etc., could significantly improve the medication safety in rural areas but, unfortunately, rural areas have not been able to adequately implement these technologies.

On the whole, the discussion of how these three topics are linked begs the need for collaboration. As was noted in the Committee's *2005 Report*, collaboration is key in addressing rural health and human service issues and this year's topics are no exceptions. Thus, while the Committee examined these issues in-depth in the individual chapters, it is important for policymakers in the Department to understand and take into account how the issues interact.

References

¹ Families USA. (2003, October 27). *Out of bounds: Rising prescription drug prices for seniors*. Families USA Publication No. 03-106. http://www.familiesusa.org/assets/pdfs/Out_of_Boundsab79.pdf.

² Committee on The Future of Rural Health Care, Institute of Medicine. (2005). *Quality through collaboration: The future of rural health*. Washington, DC: The National Academies Press.

³ Social Security Administration. (2005, September). *Fast facts & figures about Social Security, 2005*. SSA Publication No. 13-11785.

⁴ Minority Staff, Special Investigations Division, Committee on Government Reform, U.S. House of Representatives. (2000, August 17). *Prescription drug coverage, utilization, and affordability for senior citizens in California*.

Access to Pharmaceuticals and Pharmacy Services in Rural Areas

Why the Committee Chose This Topic

In simple terms, access to pharmaceuticals and pharmacy services can be seen as a process that begins when medications are manufactured and ends when consumers make appropriate use of medications. The process depends on production of medications by pharmaceutical companies, an adequate supply of medical personnel who are licensed to prescribe, an adequate supply of pharmacists or other health professionals licensed to dispense the medications, geographic access to pharmacies, and, ultimately, consumers who have the resources to purchase the medications they need. We know that chronic shortages of physicians and other health care providers are barriers to the process in many rural areas of the country. However, the broad issue of rural health manpower shortages is beyond the focus of this chapter. Instead, this chapter will focus on the more narrow issues related to pharmaceuticals and pharmacy services. The chapter will also highlight certain issues related to the financing of prescription medications, including comments on the new Medicare prescription medication benefit. Finally, it will briefly describe some Federal programs that address rural pharmacy access issues and make recommendations for strengthening or extending those programs.

In studying rural access to pharmaceuticals, the Committee analyzed the issue on several levels. As noted above, access is affected by how the medications are paid for and by whom, how they are prescribed and how they are delivered to the patient, as well as the supply of pharmacists and other pharmacy personnel in rural areas. In addition to these factors, rural areas are especially vulnerable to the rapidly changing marketplace for prescription medications and the special challenges they have created for small independent pharmacy providers in rural areas. This chapter will touch upon all of these factors, recognizing that any

one of them could be the subject of a much more thorough investigation.

Through its review of the literature and from information gathered at field meetings and site visits, the Committee has learned that current barriers to pharmaceutical access stem mainly from financial barriers. However, factors of geographic access and lack of adequate pharmacy services also play roles that contribute to the access to pharmaceuticals issue. Often these factors interact with each other to compound the challenges of access to pharmaceuticals in rural areas.

The Committee hopes that this chapter will focus the attention of policymakers on emerging issues that could have significant implications for access to pharmaceuticals and pharmacy services in rural areas of the country. The Committee believes that policymakers must be attentive to these issues and work to protect and enhance existing pharmacy resources such as Federal programs that promote increased access to pharmaceuticals and those that promote the recruitment and retention of pharmacy professionals who serve rural communities.

What Is Known About Access to Pharmaceuticals and Pharmacy Services in Rural Areas

Financial Access

Financial access to pharmaceuticals is a major issue in rural areas where a higher percentage of families lack health insurance and there are fewer employment opportunities that include insurance coverage for prescription medications. The rapidly rising cost and utilization of prescription medications is the central issue affecting financial access. Prescription medication spending nationwide increased 16 percent from 2000 to 2001. The number of retail prescriptions per capita rose from 7.9 in 1994 to 12.0 in 2004.^{1,2}

The high cost of pharmaceuticals is an especially difficult challenge for millions of low-income workers in rural areas and their families. Many of them are eligible for some coverage through public insurance programs such as Medicare, Medicaid or the State Children's Health Insurance Program. However, these programs target specific population groups such as the elderly, the disabled, and poor mothers and children. There are other rural residents who earn too much and hence do not qualify for these programs. These individuals may not be insured or may not be able to afford adequate insurance even if some coverage is provided through their employment. Part of the problem arises from the economic realities of rural America. Agriculture and small businesses dominate in rural areas and these industries tend to not provide adequate health insurance.

Many individuals without medication coverage rely on pharmacy assistance programs provided by pharmaceutical companies. These programs can provide free or low-cost prescription medications to low-income groups or individuals who meet the criteria set by the medication manufacturers. The medication industry's trade group, the Pharmaceutical Research and Manufacturers of America (PhRMA), reports that medication manufacturers donated \$4 billion in medications in 2004 by filling 22 million prescriptions nationwide.³ To date, there have been no studies of these programs that would determine whether they play a bigger role in securing prescription drugs for rural residents compared to urban or suburban residents. However, it is clear that they are a lifeline for a significant sector of the population; the Committee believes more study is needed to determine the rural implications of this pharmacy resource.

While many patients have become reliant on these assistance programs, the programs are not without their challenges. Some patient advocates believe that eligibility rules for these kinds of programs are becoming stricter and that the application process can be bureaucratic, confusing to applicants and time-consuming. Some manufacturers have cancelled or suspended their programs without notice, while others have frequently changed the types of medications that are available. These programs also work best for individuals with chronic conditions as opposed to emergent pharmaceu-

Prescription Medication Assistance Programs

Some States and private organizations have programs to assist low-income rural residents in applying for prescription medication assistance programs. One such program at the Southwest Virginia Community Health Systems, Inc. involves patient advocates who are paid to complete the application forms for patients that need financial assistance with medications. A new software program was developed specifically for this purpose. The program was so successful in its first year that the State of Virginia provided a State grant in 2002 to support and expand the program. Increased State funding has been made available in all subsequent years. In one 10-month period the program served 2,536 patients' prescriptions valued at \$3.1 million.

tical needs. Even in the best scenario, there is considerable delay between applying for these programs and receiving the prescription medications. Due to the difficulties with pharmacy assistance programs, several states have developed programs to assist patients in navigating the process of applying, whether utilizing the aid of patient advocates or software programming to streamline the process.

Individuals without medication coverage or who cannot meet their needs through pharmacy assistance programs must pay full price for their prescription medications. For rural areas, this is a concern given the higher rate of poverty of rural residents. Individuals with limited financial capabilities are more apt to forgo treatment for illnesses and chronic conditions, resulting in worse outcomes, increased hospitalizations and poorer health.

Insurers have employed a number of mechanisms to manage costs and control utilization of prescription medications, including the use of preferred medication prices that encourage the use of generic medications over name-brand medications. As prescription medication costs continue to rise and the number of pre-

Medication Access and Review Program (MARP)

The North Carolina Office of Research, Demonstrations and Rural Health Development, with funding from the North Carolina Health and Wellness Trust Fund, has developed a software program called Medication Access and Review Program (MARP) that automates the complicated process of searching for low-cost and no-cost medications available through Patient Assistance Programs for low-income patients. MARP determines patient eligibility, completes applications, tracks requests, reminds the user when it is time to reorder and provides a place for the user to maintain a permanent record of a patient's medication history. The MARP database lists more than 1,200 medications offered by more than 100 leading pharmaceutical manufacturers. MARP has been implemented in 119 clinics and has resulted in receipt of over \$20 million a year in pharmaceuticals for low-income patients in North Carolina.

scription medications continues to expand, insurers have quickly turned to tools such as pharmacy benefit managers (PBMs) to manage medication benefits and negotiate prices with the pharmaceutical companies. The PBMs have also looked for ways to reduce costs in their dealings with pharmacists by reducing dispensing fees in return for steering a higher volume of patients toward pharmacists who will contract with them directly. These kinds of strategies may be ill-suited to rural communities where there are smaller numbers of patients and pharmacists are not necessarily competing in the same way they would in urban areas. States are using similar strategies to control the rising costs of medication benefits under their Medicaid programs, and rural health policy experts are worried about the possibilities for disproportionate effects on rural Medicaid beneficiaries.

Financial Issues for Rural Pharmacies

The changing marketplace for prescription medications

has created financial challenges for rural pharmacies. Independent pharmacies, which are the more common sources of prescription medications and other pharmacy services in rural areas, are facing increased competition from chain-store pharmacies, mass merchandisers and mail-order suppliers. The rapid introduction of new medications has helped to create a marketplace based on high volumes in which the low-volume retail pharmacies that predominate in rural areas may not be able to compete. Large-volume providers exert greater leverage in negotiating discounted prices for their prescription medications. While some rural pharmacies are participating in buying cooperatives, their lower sales volumes make it difficult for them to enjoy the same pricing advantages as larger-volume providers. In addition, due to the low-volume sales, medications often spend longer times on the shelves in small pharmacies, leading to a slower recuperation of expenses for those pharmacies.

Another common complaint from rural pharmacists who testified to the Committee is the lack of transparency in pricing for prescription medications. Manufacturers offer different prices to different classes of providers and these price variations are not disclosed. Independent pharmacists in rural areas have no way of comparing their costs to those of other providers and

Wyoming's PharmAssist Program

The State of Wyoming has a unique PharmAssist Program that is being studied by other States. A coordinator receives calls from citizens, evaluates their pharmacy needs and, if required, refers the call to a pharmacist in the patient's community who will arrange a one-on-one consultation with the patient within a two-week period. The program has contracted with pharmacists throughout the State to provide this service. Clients pay only \$5 and the State pays pharmacists a \$120 consulting fee. This program is unique in that it is open to all Wyoming residents, regardless of income.

Mail-Order Medication Concerns

The Committee received formal testimonies and spoke with local rural hospitals about the issue of prescriptions being filled by mail order versus by an independent community pharmacy. One rural independent pharmacist in Wyoming, in particular, articulated that he feels pharmacists are disadvantaged in the competition with mail-order houses and other large-volume distributors where patients can obtain a multi-month supply of medications in lieu of patronizing their local independent community pharmacy for the medications and refills. Rural pharmacists testifying before the Committee raised concern that patients receiving mail-order prescriptions will not receive medication-specific counseling from a pharmacist or will seek such services from the local pharmacist who has no financial incentive to provide such services when the prescription is not filled in his pharmacy.

are handicapped in developing their purchasing options and strategies.

These emerging forces in the marketplace for retail pharmacies are raising concerns about the continued financial viability of rural independent pharmacies. While the changes predate passage of the Medicare Modernization Act (MMA), they may be accelerated as a result of the legislation. Today, third parties pay 75 percent of all prescriptions. Partly as a result of the lower reimbursements rates from third parties, most pharmacies operate on profit margins as low as 1 to 2 percent. For rural pharmacies, this poses significant difficulties because they cannot offset the small margins through increased sales.⁴ Moreover, small pharmacies with lower volumes of prescription medication sales are more dependent on the revenue generated from prescription medications. Nearly 93 percent of revenue generated by independent pharmacies is from prescription medication sales, compared with 64.6 percent in chain stores, 12.4 percent in supermarkets and 5.8 per-

cent for mass merchant outlets.⁵ This greater dependence on prescription medication revenues leaves independent pharmacies especially vulnerable to reductions in third-party reimbursements for prescription medications and competition from higher-volume suppliers. They are also more vulnerable to reductions in dispensing fees by Medicaid and private insurance carriers.

Compounding the problems of small rural independent pharmacies is their greater dependence on cash sales of prescription medications. In 2002, rural areas had a higher percentage of prescriptions paid for by cash than urban areas (18 percent vs. 13 percent).⁶ This raises potential issues concerning the new Medicare medication benefit. While the MMA will provide benefit to rural seniors, it may have negative implications for independent pharmacies. With the implementation of the MMA, Medicare beneficiaries who paid full price for medications at their local pharmacies will now have third-party pharmacy benefits. Pharmacies may be negatively affected as some of their business shifts from more lucrative cash payments to less profitable third-party payments. In addition, negative effects might occur if MMA implementation increases the use of competing mail-order suppliers. While MMA regulations state that beneficiaries must be allowed to receive benefits through community pharmacies, they may have a higher cost sharing compared to using retail outlets and mail-order suppliers.

Utilization

Utilization is a key factor in determining the issue of access to pharmaceuticals. There has been a dramatic increase in the usage of medications in the past several years prompted by direct-to-consumer advertising by the pharmaceutical industry and an overwhelming amount of information available on the Internet. Several clinicians on the Committee have expressed concerns that those two factors are changing the relationships between providers and patients, in ways that are both positive and negative. Patients may become more informed about certain medications that the clinicians might not be aware of yet. On the other hand, there is also an increased demand for clinicians to prescribe medications that might not be necessary or demand for

specific brand-name medications that can be easily substituted with generic medications.

While patients are more informed, clinicians face real challenges in navigating the increasing array of medications to treat illness and manage chronic diseases. Some insurance companies and health systems have responded by developing clinical protocols and preferred medication lists to guide clinicians in making the best possible choices based on evidence-based studies. For rural clinicians, this is particularly helpful, since many are busy and these protocols allow them to quickly sift through the ever-growing pharmaceutical options for treating a particular condition. In addition, due to the shortage of pharmacists in rural areas, many rural clinicians find themselves tackling not only the responsibilities of prescribing but also of medication counseling, tasks traditionally reserved for pharmacists.

Geographic Access and Workforce

There is currently little research on access to pharmaceuticals and pharmacy services in rural areas, but interest seems to be growing. Much of this new interest has been kindled by the rapidly rising costs and increased utilization of prescription medications, as well as the debate on Medicare coverage of prescription medications and subsequent passage of the MMA. In preparing this chapter, the Committee found some relatively recent studies on geographic access to pharmacy services in rural areas, but these studies only encompass limited areas of the country. Other studies cited describe the economic realities of rural pharmacy practice and the potential impact of changes that are occurring in the marketing, distribution and reimbursement for prescription medications. The Committee was unable to find current data on pharmacy closures in rural areas, even though (as one person testified before the Committee) rural pharmacy closures may be the “canary in the mine,” an early warning system for access problems.⁷ The Committee has noticed a decline in independent pharmacies nationwide. The need for more research on these and related issues is evident.

The Committee believes any discussion of access is tied strongly to workforce. Within that, pharmacists play a key role, but so do other health professionals,

particularly in those settings where medications are dispensed but a full-time pharmacist is not available. Physicians, physician assistants, nurse practitioners and many other health care professionals aid in helping patients to obtain necessary medications and provide necessary medication counseling.

However, the most visible face of access to pharmaceuticals and pharmacy services is still the community pharmacist. In rural areas, this can be a community pharmacist operating in his own drugstore or it can be a chain drugstore. Rural pharmacists play a key role in maintaining the health of their communities, which often exceeds their basic responsibilities for dispensing medications. In many rural communities, the local pharmacist is frequently the patient’s first point of contact with the health care system. The local pharmacist is also likely to be providing essential services under arrangements with local hospitals, nursing homes, home health agencies and other health providers. Patient counseling is also a critical component of pharmacy practice in rural areas. These services are increasing in importance as more new and modified prescription medications come to market and the rural population continues to age.

A recurring theme in the pharmacy literature is the importance of integrating pharmacists and pharmacy services with other components of the health care system. This theme was also emphasized by rural pharmacists and other experts who provided testimony to the Committee. Integration is particularly important in rural areas where health providers are in short supply. Pharmacists receive clinical training that goes well beyond the dispensing of medications. They should be viewed as part of a patient’s health management team, whether the patient is at home, in the hospital or residing in a long-term health care facility. The Committee believes that Federal programs need to promote integration.

A recent study of pharmacy services in Minnesota, North Dakota and South Dakota found that the vast majority of rural pharmacies in these States deliver prescriptions to private homes and nursing homes. Further, almost all of the pharmacies contacted in the study provided medication interaction screening services and patient education, as well as consultations with physicians and other primary care providers on medication

dosages and other patient management issues.⁸ Other studies have found that rural pharmacists have been more involved than their urban colleagues in providing cognitive, nondispensing pharmacy services.⁹ Examples include the education of patients with chronic conditions such as diabetes and assisting patients in monitoring their blood pressure. In some isolated rural communities the local pharmacist is the only health care provider. He or she may know customers on a personal

level and be familiar with their medical histories. Also, the pharmacist may be on-call 24 hours a day and would be the only readily accessible source of expertise on medication issues for local health care institutions such as hospitals and nursing facilities.¹⁰

The Committee found two studies on geographic access to pharmacy services in rural areas. Both studies covered limited areas in the Midwest and the results are not generalizable to other rural areas of the country.

A study of pharmacy services in Minnesota, North Dakota and South Dakota was published in 2002. It was based on a telephone survey of all licensed rural retail pharmacists, public health officials, clinic staff and social service workers in those States who were in communities with potential pharmacy access problems. The study also included an analysis of distances between rural pharmacies and pharmacy closures. The researchers found that the vast majority of rural residents in the three States live within 20 miles of a pharmacy and that many pharmacies help to ensure access by remaining open during evenings and weekends. While geographic access was not a significant issue in the three States, the study results raised some significant concerns about the future financial viability of rural pharmacies and shortages in the pharmacy workforce. For example, the study reported that 11 percent of the pharmacies expect to be sold during the next two years and 4 percent expected to close. Forty-six rural pharmacies closed during 1996 to 1998, with 10 closures resulting in several rural communities no longer having a pharmacy.¹¹ Although this limited data does not raise alarms, the Committee is concerned that the growing financial pressures on independent rural pharmacies, when combined with the other issues discussed in this chapter, could lead to an increase in pharmacy closures that will not be detected without greater vigilance.

A 1999 study of rural pharmacy services in 74 rural counties of Illinois found that between 1970 and 1996 there was a 17 percent loss of pharmacies overall. Among the rural Illinois counties, 44 lost pharmacies, 20 experienced a gain and the average population served by individual pharmacies increased significantly. The study concluded that while current access to a local pharmacy remains good, a further decline in rural pharmacies could erode access to the range of services of-

HRSA's Study of the Pharmacy Workforce

The HRSA study of the pharmacy workforce discussed several factors that distinguish rural pharmacy practice and create problems in recruitment and retention of pharmacy personnel:

- 1) Isolation from other health professionals;
- 2) Low profit margins of community pharmacies and lower potential earnings for pharmacists;
- 3) Competition from large retail chains and mail-order houses;
- 4) The growing number of women pharmacists and the difficulties rural communities might have in meeting their family and professional needs;
- 5) Isolation from pharmacy and pharmacy technician schools;
- 6) The disproportionate number of Medically Underserved Areas in rural America that forces residents to seek medical care elsewhere, including purchase of prescription medications;
- 7) The nationwide conversion from Bachelor of Science Degree in pharmacy to the Doctor of Pharmacy Degree that has lengthened the education program for pharmacists.

Identifying Rural Pharmacies At Risk for Closure

The College of Pharmacy at the University of Minnesota has developed a protocol for identifying rural pharmacies at greatest risk of closure. There were four factors used to generate the risk assessment score for each of the pharmacies surveyed.

- 1) The distance to the nearest pharmacy patients would have to go if the surveyed pharmacy closed, with the greater the distance, the higher the risk score;
- 2) The difference between the age of the pharmacy owners and the ideal age when they would have liked to sell their pharmacy. The study observed that many pharmacy owners maintain their pharmacies beyond the age that they would have liked to sell;
- 3) Total pharmacy revenues;
- 4) The difficulty in recruiting pharmacists to rural areas.

ferred by local pharmacies and many residents may lose another health professional and source of health information in their community.¹²

Both of the studies described above noted that reduced access to pharmacy services may cause rural consumers to forego essential treatments with prescription medications and deprive them of professional help in preventing and resolving medication-related health problems. They emphasized that the rural elderly are especially vulnerable because of their high rates of prescription medication usage and greater likelihood of experiencing transportation problems.

Maintaining geographic access to pharmacy services in rural areas depends upon an adequate supply of health care providers, including pharmacy personnel. Currently, the pharmacy workforce is not evenly distributed across the country. Only 12 percent of pharma-

cists practice in rural areas even though 21 percent of the country's population is in rural areas.¹³ Moreover, while the national ratio is 78 pharmacists per 100,000 people, the rural ratio is only 66 pharmacists per 100,000 people.¹⁴

In 2000, a report to Congress on the nation's pharmacy workforce prepared by HRSA found that during the 1990s the demand for pharmacists began to exceed the supply. At the same time, the use of prescription medications had increased rapidly. The report showed that the average number of prescriptions handled by retail pharmacists increased by 31.4 percent from 1992 to 1999.¹⁵ There is nothing in the current research literature to suggest that growth in the use of medications and demand for pharmacists is slowing.

The same HRSA study cited a decline in the number of pharmacy graduates during the 1990s and a corresponding decline in the number of applications to pharmacy schools. However, this situation appears to have changed. Data from the American Association of Colleges of Pharmacy indicate that the number of applicants increased in 2004.¹⁶ At the same time, the number of pharmacy schools has grown to 96, with more schools expected to open in the next few years.¹⁷ Despite these trends, the U.S Department of Labor includes pharmacists among the high-demand occupations where job vacancies will exceed the supply of candidates for the foreseeable future.¹⁸

Some studies have raised concerns about the high proportion of aging pharmacists in rural areas and what this means for the future. One study in Minnesota found that the average age of pharmacists who owned pharmacies in rural areas was 52.8 years and that a significant number of pharmacists would like to sell their pharmacy in three years or less.¹⁹ Concurrently, a survey of pharmacy students revealed their concerns about lifestyle limitations and their lack of interest in pharmacy ownership.²⁰ The analysis suggests that when these aging independent rural pharmacists retire, their pharmacies will close permanently, leading to a loss of access to pharmaceuticals and pharmacy services for many rural communities.

Pharmacy technicians are also a vital part of the pharmacy workforce. They dispense medications with the supervision of a pharmacist, whether it is directly or via telepharmacy. The distribution of pharmacy tech-

Alaska Native Medical Center Telepharmacy Program

The Alaska Native Medical Center has developed a unique telepharmacy program to help address the pharmacy needs of seven Community Health Centers in South-central Alaska and the Aleutian Islands. Due to their remote, frontier nature, these sites cannot rely on traditional pharmacy services; therefore, telepharmacy has been the means through which these communities have access to pharmaceuticals. Pharmacists in Anchorage view the medication orders and authorize the dispensing via teleconference. Patients are counseled either via telephone or televideo.

nicians vary throughout the country, with certain states utilizing Pharmacy Technician Certification Boards whereas others do not. There has been limited research on pharmacy technicians and their potential role in helping to alleviate the pharmacy personnel shortage. A key factor of the issue is that pharmacy technicians are not considered extenders of care, such as physician assistants are for physicians; rather, pharmacy technicians require pharmacist supervision.

Pharmacy Services in Rural Hospitals, Nursing Facilities and Extended Care Facilities

There are major differences between large and small hospitals in the extent of pharmacy services they provide. A national survey of pharmacy practice in hospital settings conducted by the American Society of Health System Pharmacists found that few small hospitals provide the 24-hour inpatient pharmacy services that larger hospitals provide. Among small hospitals with less than 50 beds, only 1.5 percent provided 24-hour service, while 95.6 percent of hospitals with more than 400 beds provided this coverage. In addition, pharmacists' review of medication orders was less prevalent in small hospitals—reviews were made in 5.9 per-

cent of hospitals with less than 50 beds, as opposed to 92 percent of hospitals with more than 400 beds. The survey also showed that medication therapy management services are less likely in smaller hospitals.²¹ (See the table on the next page, “Hours of Inpatient Pharmacy Operation per Week”).

Rural nursing homes and extended care facilities often contract with local pharmacies or regional suppliers for their pharmaceuticals. The Committee visited an independent pharmacy in Johnson City, Tennessee that serves health care providers located in surrounding isolated areas of Appalachia. The pharmacy was using advanced automatic dispensing technology to provide pre-packaged pharmaceuticals and other biologicals for individual patients in nursing homes and extended care facilities. It provides consultation and expertise to local physicians, institutional providers and individual patients on a wide range of issues, including medication safety, medication management, options for prescription medications and other issues. These relationships took many years to be forged, thus there is concern that emerging market forces and Medicare Part D could disrupt long-standing relationships between this pharmacy and the patients and providers it serves as many consumers enroll in mail-order medication programs. In addition, this site visit illustrated the strength of marrying health information technology with quality pharmacy services. In its study concerning pharmacist staffing in rural hospitals, the Upper Midwest Rural Health Research Center concludes that the usage of information technology increases the safety of medication dispensation; this site demonstrated the feasibility of such a link.²²

Current HHS and Governmental Role

HHS plays a significant role in the delivery of pharmaceutical services through its administration of the Medicare, Medicaid and State Children's Health Insurance programs.

Medicare

The medication benefit that began in 2006 has the potential to vastly improve financial access to prescrip-

Hours of Inpatient Pharmacy Operation per Week

Hours of Inpatient Pharmacy Operation per Week (% Hospitals) (% Hospitals)

Characteristic	n	Mean ± S.D.	Range	<56 hr	56-83 hr	84-111 hr	112-167 hr	168 hr
All hospitals	492	101.3 ± 49.3	0-168	21.5	26.6	13.4	7.9	30.6
Staffed beds								
<50	61	54.3 ^a ± 24.1	0-168	62.3 ^b	29.5	6.6	0.0	1.6
50-99	89	78.6 ± 29.0	0-168	11.2	59.6	19.1	4.5	5.6
100-199	80	108.6 ± 37.7	40-168	3.8	28.8	27.5	17.5	22.5
200-299	79	151.4 ± 28.8	71-168	0.0	2.5	10.1	15.2	72.2
300-399	93	161.6 ± 17.7	80-168	0.0	1.1	1.1	10.8	87.1
≥400	90	164.7 ± 16.0	67-168	0.0	2.2	1.1	1.1	95.6

^aDesign-based $F(1,486) = 1250.72, p < 0.0001$.

^bUncorrected $\chi^2 = 491.06, d.f. = 20, \text{design-based } F(1261, 6126.57) = 29.19, p < 0.0001$.

Source: Testimony to the National Advisory Committee on Rural Health and Human Services by the Association of Health-System Pharmacists, August 16, 2005. (2004 Association of Health-System Pharmacists National Survey).

tion medications for senior citizens in rural communities. Prior to the passage of the MMA, more than a third of Medicare beneficiaries had no prescription medication coverage.²³ Historically, rural Medicare beneficiaries have had more difficulty affording medications than urban beneficiaries. In 1999, one-half of all rural seniors had no prescription medication coverage compared to only one-third of urban seniors. Adding to the difficulties of rural Medicare beneficiaries is the fact that they often need more prescription medications than urban seniors due to a higher prevalence of chronic conditions.²⁴

The Committee is encouraged by the number of pharmacy plans that are available in rural areas in addition to the 11 national plans. It is clear that HHS is actively working to bring access to pharmaceuticals and pharmacy services to many Medicare beneficiaries.

However, rural researchers and policy advocates have identified concerns about how the program will be implemented in rural areas, with many of the concerns centering on the access issue. The MMA adopted access standards used by the TRICARE Retail Phar-

macy Program that insures military health care beneficiaries. In rural areas, the TRICARE standard for access is that at least 70 percent of beneficiaries must live within 15 miles of a retail pharmacy. In other words, 30 percent of rural Medicare beneficiaries can live more than 15 miles from a pharmacy and the standard might still be met. Depending on how the standard is implemented, about 7.8 million rural beneficiaries may not have access to a network pharmacy.

Providers of the Medicare drug benefit must include in their network “any willing pharmacy” that can meet the providers’ terms and conditions. Some rural pharmacies may not be able to meet the requirements (i.e., information processing capabilities) and could be excluded from the networks.

Another concern is that rural residents have little prior experience selecting from multiple insurance plans. Under the new Medicare medication benefit, beneficiaries will have to make difficult and confusing choices among competing plans that are offering different pre-approval requirements, different formularies for covered medications, different access points and

other variables. A related concern is that the penalty for late enrollment may disadvantage rural beneficiaries if they delay enrolling because they have more limited access to information and assistance in making plan choices. Beneficiaries will need access to information and assistance in understanding plan options.

Finally, there is the concern that rural seniors who are dually eligible for Medicare and Medicaid may be adversely affected by the MMA in some States. Under the law, seniors in some States will be moving from generous Medicaid medication coverage to less generous coverage under Medicare.

The validity of these concerns will not be known until the new benefit begins. The Committee will be tracking MMA implementation issues in rural areas over the next few years.

Medicaid and SCHIP

Medicaid and SCHIP (State Children's Health Insurance Program) enrollees in rural areas are vulnerable to the rising costs of prescription medications and the resulting efforts to control these costs. In recent years, the Medicaid program has experienced a rapid increase in spending for prescription medications. Between fiscal years 1997 and 2002, Medicaid's expenditures on medications in the fee-for-service part of the program increased at an average annual rate of 18 percent. Consequently, policymakers at both the Federal and State levels are considering ways to moderate that growth.²⁵

Some States have already taken action. According to a study by the HHS Office of the Inspector General, 17 of 43 States responding to a 2003 survey had recently reduced their Medicaid reimbursements for prescription medications.²⁶ States adopted a number of different strategies to reduce their costs, including lowering their medication acquisition costs, implementing maximum allowable costs for certain classes of medications, adopting more restrictive medication formularies and reducing dispensing fees paid to pharmacists. Further, many States have tried to control costs by freezing or reducing provider payments, restricting eligibility to certain populations, adding cost-sharing requirements and other strategies.

Many rural advocates believe that these cost-cutting measures will have a disproportionate effect in rural

areas because the percentage of the rural population dependent on Medicaid is proportionally greater than for urban areas.²⁷ Further, there are proportionately more rural elderly receiving Medicaid (10.1 percent) than urban elderly (8.2 percent); hence, with the reduction in Medicaid benefits, the elderly in rural areas will be affected more. Efforts to control pharmacy costs also could create unique access barriers in rural areas because rural pharmacists are more reliant on Medicaid reimbursement than urban pharmacists.²⁸

In addition to Medicare and Medicaid, HHS administers other significant programs to improve access to pharmacy services in rural and urban areas.

340B Program

Administered by HRSA since its creation in 1992, the 340B Drug Pricing Program (340B) enables certain federally funded safety net providers to obtain significant discounts on outpatient drugs. On average, 340B drugs cost 20 to 40 percent less than the Average Wholesale Price (AWP). A variety of entities including Federally Qualified Health Centers, Urban Indian Health Centers, Family Planning Clinics, Hemophilia Treatment Centers and other covered entities are eligible to participate in 340B. In addition, publicly owned non-profit Disproportionate Share Hospitals (DSHs) with a DSH adjustment percentage greater than 11.75 can participate in 340B, and private non-profit DSH hospitals may also participate in 340B if they contract with a State or local government to provide uncompensated care. Critical Access Hospitals and federally designated Rural Health Clinics are currently ineligible to participate in the 340B Program.

Prior to the 2003 MMA, most rural hospitals with under 100 beds were ineligible for the program. However, effective April 1, 2004, Section 402 of MMA raised the DSH adjustment rate cap for most rural hospitals to 12 percent, making approximately 360 small rural and urban hospitals that provide a significant amount of charity care eligible to participate in 340B. As of October 2005, only 120 hospitals (30 percent) have enrolled in 340B. Although the number of hospitals participating in 340B is growing slowly, the Committee is concerned about why more hospitals are not taking advantage of this beneficial program.

Some potential barriers to participation include:

- 1) The need for private non-profit rural DSH hospitals to have a written agreement or contract with State or local government to provide uncompensated care;
- 2) The confusion regarding participation in group purchasing organizations;
- 3) The program's non-coverage of inpatient medications;
- 4) The confusion about program benefits;
- 5) The perception that the program is complicated and overly burdensome.

The Office of Rural Health Policy and the HRSA Office of Pharmacy Affairs are working together to promote the benefits of 340B to eligible rural hospitals and increase enrollment in this cost-saving program, which can help increase access to affordable medications for rural patients.

Telepharmacy Programs

HRSA, through its Rural Telemedicine Network Grant program and through annual earmarked grant projects, has also invested in a number of telepharmacy projects. This program and its grant-making authority provide another mechanism for rural communities seeking to expand pharmacy services through the use of telecommunications technologies. One example is a program conducted by a Federally Qualified Community Health Center in Spokane, Washington that involves the dispensing of low-cost medications obtained through participation in the 340B program discussed above. The program uses a two-way interactive video conferencing system for centralized management and supervision of the dispensing of prescription medications to patients at six urban and rural clinics. The project is taking advantage of a decision by the State Pharmacy Board that allows pharmacy technicians and nurses to dispense medications under long-distance supervision using telecommunications technology. Another example is a program at the North Dakota College of Pharmacy at the University of North Dakota. This project allows a li-

censed pharmacist at a central site to supervise a registered pharmacy technician at a remote rural site in processing prescription medications for patients.

National Health Service Corps Demonstration

Three years ago the National Health Service Corps initiated a demonstration project that placed 24 pharmacists in medically underserved areas of the country. Roughly an even number of pharmacists were placed in rural and urban areas. In addition to their salaries, the pharmacists receive \$35,000 per year for the first two years to pay back their education loans, and each subsequent year they receive at most \$25,000 until the loans are repaid. There was no standard within the program to determine whether the areas where the pharmacists were placed were underserved in terms of pharmacy professionals. However, the demonstration did require the presence of a National Health Service Corps physician in each area where a pharmacist was placed. The lack of a standard to identify pharmacist shortage areas makes it difficult to evaluate the need for further placements by the Corps. Appropriate standards would be required for a legislative expansion of the Corps to authorize the recruitment and placement of pharmacists. A report on the pharmacist demonstration will be available from HRSA in September 2006.

Quentin Burdick Interdisciplinary Grants

This program administered by HRSA supports grants for developing new and innovative methods and models for training health care professionals to provide services in rural areas. Several projects include training in pharmacy services. The program allows for increased recruitment and retention of health care professionals, including pharmacists, in rural communities. Moreover, since the program emphasizes interdisciplinary cooperation and work, the pharmacists who participated in these programs tend to collaborate more extensively with other health care professionals, a characteristic that is crucial for rural areas.

HIV/AIDS Drug Assistance Program

In 2002, about 128,000 AIDS patients received medications through HRSA's AIDS Drug Assistance Program. In 2003, there were 52,000 AIDS cases reported in rural areas compared with 808,000 cases in urban communities.²⁹ States determine eligibility for the program and employ different strategies for distribution of the medications. Some use local pharmacies as the point of distribution. The program is becoming more significant for rural areas as the number of AIDS cases increases there.

Rural Health Outreach and Network Development Grants

These two programs support innovative projects for integrating health care services in rural areas. Both programs have supported a limited number of projects that include pharmacy services. Though not specifically geared toward pharmacy issues, these grants do provide some funding to programs that seek to increase recruitment and retention of pharmacists and increase access to pharmaceuticals and pharmacy services in rural communities. Many of the Outreach and Network Development grants that contain pharmacy-related projects aim to obtain free or reduced-cost drugs for the low-income and uninsured in their local communities.

Area Health Education Centers

These academic-community partnership centers concentrate on training health professionals to focus on specific local and State health needs. The program seeks to improve the supply, distribution, diversity and quality of health professionals to serve underserved populations. In that capacity, Area Health Education Centers promote the recruitment and retention of health care professionals, including pharmacists, to medically underserved areas, both urban and rural. The Area Health Education Centers design programs that promote interdisciplinary studies, with trainings coordinated among primary care physicians, nurses, pharmacists and other health professionals.

Agency for Healthcare Research and Quality

The Agency for Healthcare Research and Quality (AHRQ) is the lead Federal agency on quality of care research. AHRQ coordinates, conducts and supports research into measurement and improvement of health care quality. One of the ways that AHRQ accomplishes these goals is through utilization of Evidence-Based Practice Centers that focus their research on the effective delivery of health care in the nation. There are 12 Evidence-Based Practice Centers that develop evidence reports and technology assessments on clinical, social science/behavioral and economic topics related to the effectiveness of health care delivery. Though the centers have not focused specifically on the issue of access to pharmaceuticals, they do address such topics as medication errors, medication management and health care costs containment, all topics related to the discussion of pharmaceuticals and pharmacy services access.

Conclusion

The Committee chose this topic because it believes that access to pharmaceuticals and pharmacy services is a pressing issue for rural communities and it is likely to become more important in the future. During its investigation of this topic, the Committee acquired a keen appreciation for the vital services that rural pharmacists are providing in their communities. It is clear from the literature and from the Committee's first-hand experiences with these providers that they are rendering services that go far beyond the dispensing of medications. In rural communities, the local pharmacists are more likely to be closely involved with the overall health care needs of patients and their families than their counterparts in urban areas. They are indispensable assets in rural communities. It is a potentially significant problem that the nationwide demand for pharmacists currently exceeds the supply. If this disparity becomes worse over time, as many projections suggest, rural areas may begin to experience significant pharmacist shortages.

In addition, changes in the marketplace for pharma-

ceuticals that were highlighted in this chapter, including the growth of third-party payments and competition from mail-order distributors and large commercial suppliers, are major threats to the continued viability of rural independent pharmacies. When a rural independent pharmacy closes, the community is likely to lose necessary services such as medication counseling and emergency medication dispensing, which could adversely affect rural residents. This issue must be closely watched over the coming years.

Recommendations

The Committee encourages the Secretary to ensure continued access to pharmaceuticals and pharmacy services in rural areas through the following recommendations:

Department Grant Programs:

- *The Secretary should include rural pharmacy services as a focus for existing Departmental grant programs.*

The Committee has identified several grant programs in the Department that could be used effectively to promote and support access to pharmaceuticals and pharmacy services in rural areas. These include the Quentin Burdick Interdisciplinary Grants authorized under Title VII of the Public Health Service Act; the Rural Health Network Development Grants authorized under Title II, Section 330A of the Public Health Service Act; the Rural Health Outreach Grants authorized under Title II, Section 330A(f) of the Public Health Service Act; grants to support schools of pharmacy authorized by Title VII of the Public Health Service Act; and the 340B Medication Discount Program. The Secretary should identify other programs as well. Programs with appropriate authorizations should encourage applications from qualified organizations that can present innovative ideas for improving or sustaining access to pharmaceuticals and pharmacy services in rural areas, and for integrating pharmacy services with other components of rural health care delivery systems.

National Health Service Corps:

- *The Secretary should seek authorization to allow pharmacists to be eligible for the National Health Service Corps, and to provide the funding for the National Health Service Corps to provide them with scholarships and loan repayments options.*

The National Health Service Corps recently completed a demonstration program that placed a small number of pharmacists in underserved areas of the country. The Committee believes that the mission of the Corps should now be expanded to include pharmacists among the other health professionals eligible for loan repayments, scholarships and placements through the Corps. Moreover, the Committee is aware of the potential difficulties posed by the lack of criteria for designating pharmacist shortage areas in rural parts of the country. The Committee believes, however, that the existing criteria for designating Health Professionals Shortage Areas are a reasonable proxy for shortages of pharmacists and could be used by the Corps until such time as more specific criteria could be developed.

Area Health Education Centers (AHEC):

- *The Secretary should use the AHEC program to promote and support programs to better integrate rural pharmacy providers with other components of rural health care delivery.*

The AHEC program has been, and continues to be, an effective source of support for educational programs and other efforts to help rural communities and rural health care providers develop more integrated systems of care. The critical role of pharmacy providers in rural areas and the need for them to become a more integral part of local health care delivery systems should be recognized and supported through the AHEC program.

Workforce Studies:

- *The Secretary should require workforce studies conducted by the Health Resources and Services Administration to analyze any potential differentials between rural and urban in terms of health professions*

workforce. The Secretary should also charge HRSA to conduct a follow-up study to the 2000 pharmacy workforce report.

In presenting this chapter, the Committee was able to use some limited information from a major study of the nation's pharmacy workforce conducted by HRSA in 2000. That study (and others like it) did not provide data on urban and rural differences in the pharmacy workforce. The Committee believes that any future studies should attempt to identify and present workforce data that allows comparisons between urban and rural areas. Further, the Committee recommends that the Secretary require HRSA to do an analysis of the urban/rural distribution of pharmacists in 2006. This study is critical given the projected disparity in the nation's supply and demand for pharmacists.

Evidence-Based Practice Research:

- *The Secretary should support research on the potential risks of pharmacy closures in rural communities using Evidence-based Practice Centers supported by the Agency for Healthcare Research and Quality.*

The Committee has found that more research needs to be conducted as to the potential factors that might place a rural community at risk of losing their local pharmacy. In identifying those issues, the Committee believes it will be easier to develop programs to target those risks.

The 340B Drug Pricing Program:

- *The Secretary should recommend to Congress that the list of eligible entities for the 340B Drug Pricing Program be expanded to include Rural Health Clinics and Critical Access Hospitals.*

Under the 340B program, rural health clinics should qualify if they operate on a sliding fee scale and Critical Access Hospitals should qualify if they show that they have a Disproportionate Share Percentage greater than 11.75 percent if paid under the Medicare Inpatient Prospective Payment System. Rural Health Clinics and Critical Access Hospitals that meet these crite-

ria must be considered a vital part of the health care safety net in rural areas and should be recognized as such under the 340B program.

The Committee also recommends that the Secretary provide additional resources to the HRSA Office of Pharmacy Affairs that administers the 340B program. Throughout the year, the Committee received testimony that many entities eligible for the program are not aware of its benefits or have been unable to seek participation because of staffing limitations and other factors. Further, these entities often need technical assistance related to administration of the program at the local level. Presently, the Office of Pharmacy Affairs lacks sufficient resources to provide effective outreach to eligible entities and the technical assistance they require.

Moreover, the Committee recommends that the Office of Pharmacy Affairs should conduct a study to determine the extent of urban and rural differences in participation in the program and take steps to provide appropriate assistance to eligible rural entities.

Medicare:

- *The Secretary should support an annual study for the next five years that examines the impact of the Medicare Modernization Act on rural pharmacies and rural residents' access to pharmaceuticals and pharmacy services.*

In this chapter, the Committee has discussed some concerns about the potential impact of the new Medicare Modernization Act on rural seniors and pharmacy service providers. The validity of these concerns will not be known until the new benefit has been implemented and tested. However, the Committee believes that rural areas pose unique challenges for the program and there is the potential for problems to surface over the next few years. The Committee believes that the Secretary should support studies and monitoring systems to determine how well the program is serving rural beneficiaries and pharmacy providers so that problems can be identified and resolved at the earliest possible time. There may be opportunities to integrate such studies with other efforts that are already planned.

- *The Secretary should conduct a demonstration to examine the use of Medicare payments in providing medication therapy management services to seniors who are taking multiple medications.*

The Committee recommends that the Secretary conduct a demonstration program to examine the use of Medicare payments to provide medication therapy management services to seniors who are taking multiple medications and are at greatest risk for negative drug interactions. Medication therapy management services can have a significant impact on the health of seniors who are at high risk for negative drug interactions and other complications stemming from dependence on multiple medications. Demonstration programs should be conducted to identify those seniors most at risk in both the Medicare fee-for-service and Medicare Advantage settings. Such programs would also help to identify positive outcomes of medication therapy management services, as well as their impact on the cost of the Medicare program.

Telepharmacy:

- *The Secretary should evaluate the impact of telepharmacy projects in rural areas.*

The Committee believes that telepharmacy has the potential to increase access to pharmaceuticals and pharmacy services, particularly in communities that are unable to establish and sustain pharmacy services due to low population density, unfavorable economic circumstances, geographic isolation or other factors. However, the Committee is concerned that telepharmacy applications must improve access without compromising the quality of services that are available. The Committee believes that more information is needed on how well telepharmacy applications are balancing the issues of access and quality in rural areas. The evaluations should include studies on best practices and outcomes.

Pharmaceutical Assistance Programs:

- *The Secretary should evaluate existing software programs that have been developed to assist low-income citizens in obtaining access to prescription medications through pharmaceutical assistance programs*

offered by pharmaceutical manufacturers. After a thorough examination, the Department should disseminate information on these programs to Federally Qualified Health Clinics, Rural Health Clinics and other providers serving rural areas.

During its work on this chapter, the Committee received testimony describing several recently developed software programs designed to help low-income groups identify pharmaceutical assistance programs available to them and streamline the application process. The Committee also learned that many safety-net providers have been unable to aid their patients in applying for pharmaceutical assistance programs due to staffing limitations. Thus, these software programs would be able to mitigate that issue. The Committee believes that the Department can play an important role in identifying successful software programs, disseminating information about them and assisting providers in their implementation.

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Health Information Technology in Rural Areas

Why the Committee Chose This Topic

In April of 2004, President George W. Bush issued an Executive Order calling for most Americans to be connected to an electronic health record within ten years.¹ In order to implement this ambitious plan, the Office of the National Coordinator on Health Information Technology (ONCHIT) was created under the Department of Health and Human Services (HHS). HHS Secretary Mike Leavitt has made this one of his key priorities.

Before this Executive Order, concerns over health information technology (HIT) needs could be heard throughout the United States in various discussions about health care quality, medical errors, access to care and population health—and rural areas have not been an exception. Discussions on HIT have ranged from technology such as bar coding and computerized provider order entry to the provision of direct clinical care via telemedicine and telehealth technologies. For the purposes of this chapter, the Committee will use the definition of HIT as set forth by the Office of the National Coordinator. ONCHIT defines HIT as “the application of information processing involving both computer hardware and software that deals with the storage, retrieval, sharing, and use of health care information, data, and knowledge for communication and decision making.”²

Based on this definition, it is clear that HIT presents a number of opportunities for improving the health of rural Americans. HIT has the ability to help disparate rural providers from across the spectrum of care to better coordinate care for their patients. It also has the ability to help rural communities improve public health through disease surveillance and targeted health education. HIT presents the opportunity to compile regional data that can be used to improve the health of rural Americans. In addition, HIT with decision sup-

port tools has the great ability to improve the quality of health care not just in rural communities, but also across America. A recent Institute of Medicine (IOM) report³ argues that investing in HIT in rural America has the ability to help meet the six quality aims set forth in the original (IOM) *Crossing the Quality Chasm* report:⁴ make health care safer, more effective, patient-centered, timely, efficient and equitable. These tools can be especially useful for rural Americans who travel to numerous providers to seek care. Beyond quality of care, HIT has the ability to improve population health, monitor chronic disease and improve access to health care in rural areas.

Despite the discourse surrounding the myriad of HIT options, the focus of the President and ONCHIT has been on electronic health records (EHRs). Given the President’s and the Department’s focus on EHRs and the commitment of the Office of the National Coordinator to achieving the President’s goal of connecting most Americans to an EHR by 2014, the Committee has chosen to focus on the impact of EHR development in rural America. Although this chapter focuses on EHRs, it is also important to reiterate that the full range of HIT extends beyond EHRs. For example, within the HIT movement there are those developing more advanced forms of telehealth and telemedicine to connect clients to specialists.

What makes this national issue especially pertinent to rural communities is that EHR adoption and use are not equal across health providers. The adoption of HIT generally, and EHRs more specifically, is moving at a much different pace in rural communities than in urban and suburban communities. Dr. David Bailer, National Coordinator for Health Information Technology, explains:

My concern is not low EHR adoption, but variable EHR adoption. Clinicians are indeed using EHRs today, but some clinicians are adopting EHRs more readily than others—creating an

adoption gap based on the size of practice...if we believe that EHRs improve health status—as evidence says they do—then we have an obligation to level the playing field so that all practices and hospitals can adopt these life-saving tools.⁵

Based on the literature as well as discussions with rural providers, there is a general consensus that rural America cannot afford to be left behind in the adoption of this technology. At the same time, many rural providers lack the resources of their urban and suburban counterparts, and that makes any investment in EHRs a potential risk given their limited capital for HIT investment coupled with the rapid change in technology and the dearth of accepted national technical standards. Scalability is also a factor in rural HIT adoption; some rural providers may see the need for some base-level technology such as email or a computerized disease registry before the use of EHRs. However, many rural providers have already made an investment in HIT, and the Committee has had the opportunity to witness the diversity of HIT adoption in rural America through site visits over the past year.

The Committee supports the Secretary and the National Coordinator’s efforts to spur EHR adoption, but also hopes that this chapter will help inform the larger national discussion by identifying some of the challenges faced by rural communities. The Committee urges the Secretary and the National Coordinator to keep in mind that there are key differences between rural and urban health care systems that will have sig-

nificant implications for EHR adoption. The reality is that rural health systems are not just a small version of suburban and urban health systems. Rural communities face a number of challenges, including infrastructure, service and provider mix, health status and socioeconomic characteristics that are different than urban and suburban areas.

The Office of the National Coordinator for Health Information Technology has produced a Framework for Strategic Action that is being used to guide the implementation of EHRs across America.⁶ As an Advisory Committee to the Department of Health and Human Services, the Committee felt it would be appropriate to structure the discussion about rural HIT around the four goals of this framework.

What Is Known About Health Information Technology in Rural Areas

The Framework for Strategic Action outlines the following four broad goals for the implementation of HIT:

- Inform clinicians
- Interconnect clinicians
- Personalize care
- Improve population health

The Framework specifically focuses on the implementation of EHRs to achieve the four goals. While the exact definition of an electronic health record was not outlined in the report, the following definition helps to explain the purpose of EHRs: “EHRs were originally envisioned as an electronic file cabinet for patient data from various sources...Now they are generally viewed as part of an automated order-entry and patient-tracking system providing real-time access to patient data, as well as a continuous longitudinal record of their care.”⁷

In this chapter, the Committee hopes to emphasize that the unique circumstances regarding the size and limited infrastructural capabilities of rural communities mean that rural health providers face unique risks when deciding to adopt HIT. For rural communities,

National HIT Strategy: Four Goals of the Framework for Strategic Action

- Inform clinicians
- Interconnect clinicians
- Personalize care
- Improve population health

this issue is much larger than just using technology to improve care; use of HIT will help to determine the future landscape of rural health. In the context of the Framework for Strategic Action, this means that the phases of implementation of EHRs will be much different for rural communities than other parts of the United States.

While this section is structured around the Framework for Strategic Action, there are a number of specific rural concerns about HIT that inform the Committee's analysis of the four goals. The capital required to invest in HIT systems in addition to the capital resources needed to sustain the systems are a major concern for rural providers. While urban and suburban providers may already have some hardware and infrastructure in place to ease the financial transition to HIT, rural providers may not have the same access to these resources. In addition, the prospect of major shifts in workforce due to lack of expertise and/or sheer numbers of employees make HIT adoption difficult for rural providers. Technical assistance is needed for any information technology investment, but for rural providers without an information technology (IT) department housed in their facility, this assistance comes with an additional cost. These are just a few of the broader concerns the Committee hopes to emphasize as ONCHIT moves forward on the four goals of the Framework for Strategic Action.

It is also important to note that we do not know a lot about HIT in rural communities because of a general lack of data on the adoption rates in rural America. Much of the analysis provided here is based on conversations with rural providers and some limited data sources.

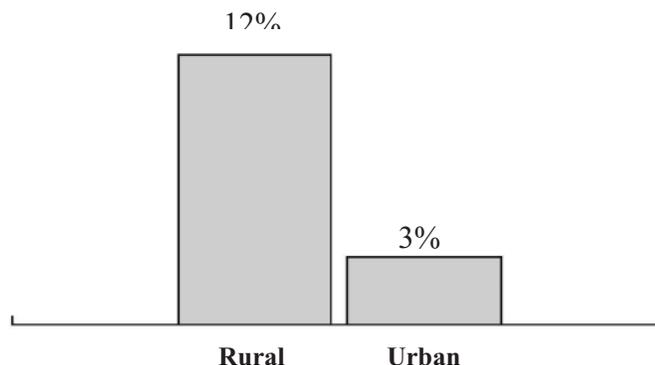
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Goal One: Inform Clinicians

The Framework for Strategic Action outlines the following strategies for informing clinical practice through the use of EHRs: incentivize EHR adoption (making a business case for adoption); reduce the risk of EHR

Rural hospitals less likely to be using or considering clinical IT

Percent of hospitals not using or considering use of clinical IT by location



Source: *Forward Momentum: Hospital Use of Information Technology*. American Hospital Association, pg. 1. <http://www.ahapolicyforum.org/ahapolicyforum/resources/content/FINALNonEmbITSurvey105.pdf>.

investment; and promote EHR diffusion in rural and underserved areas.⁸ While this goal mentions rural health providers, it is important that even incentivizing and reducing the risk of EHR adoption in rural communities is challenging because of infrastructure limitations and the difficulty of creating a business case for adoption. The Committee believes that one of the major issues facing rural providers in looking at the possibility of adopting HIT is whether they have or can create the economies of scale necessary to handle the large investments.

While we do not know the exact HIT adoption rates in rural America, recent data suggest that rural areas lag behind in even considering HIT. A recent American Hospital Association survey of community hospitals found that of the hospitals not even considering the use of HIT, 82 percent were rural.⁹ With regards to EHR use, the study found that of the hospitals that had not fully or partially implemented any EHR functions, 75 percent were rural.¹⁰ While these numbers are specific to hospital use of HIT, they are still demonstrative of the challenges HHS and ONCHIT face in achieving the goal of informing clinical practice in rural settings.

Not investing in HIT early on is a rational response on behalf of many rural providers given the great risks

Community Network Purchasing of HIT

Community purchasing of HIT has made recent headlines as rural communities are finding unique ways of making HIT a reality. The Taconic Health Information Network and Community in rural upstate New York is a group of 500 doctors who joined together to create an online electronic record for their patient information. Similarly, a group of rural Montana providers joined forces to purchase IT systems to improve not only clinical care, but also administration efficiency. This group (HealthNet) has a central IT staff to monitor activities at each of the facilities. Both of these groups are examples of local efforts aimed at making HIT purchasing more realistic for rural providers of all sizes through collective purchasing.

involved with adoption. The reality is that many rural providers struggle with a range of challenges from financial viability and capital acquisition to workforce shortages. For those providers, thinking strategically about investing in HIT may not be the highest priority. At the same time, there are other providers that, while struggling with some of the same daily challenges, realize that it might be in their best interest to start thinking long-term about how to use technology to improve patient care. In addition, return on investment in EHR development at this stage is difficult to gauge not just financially, but in terms of quality. Many rural providers are waiting for the certainty that investing in EHRs will not only increase their bottom line in the long run, but improve quality and patient safety overall.

It is also important to note that not all rural providers are starting from a blank slate in terms of adoption. Many facilities have some form of a legacy system that may already dominate workplace culture. With the push toward EHRs, integrating old systems with new systems is an issue facing rural communities as well as their urban and suburban counterparts. In addition, there is a range of experience across rural America on

HIT; the lack of a business case does not rely on the absolutes of adoption versus non-adoption. The Committee believes that the Strategic Framework does not consider the diversity of experience that exists in the health care field on HIT and how that diversity impacts incentivizing adoption of HIT.

In order to use HIT to inform clinical practice in rural settings, the assumption that technology infrastructure already exists for all health providers must be addressed. Upfront investment of the infrastructure required to even consider having HIT makes creating a business case for EHR adoption very difficult for rural providers that may lack tools such as computers or high-speed Internet access, or that lack of training in using these tools.

Unfortunately, there has not been a lot of research done on the extent of technological and Internet infrastructure in rural communities. However, research that has been done shows that the costs for companies to bring high-speed Internet to rural areas provide a disincentive for deployment. While small rural towns are more successful in obtaining infrastructure than remote areas outside of those towns, the rates of deployment still lag far behind suburban and urban areas. For example, in the year 2000 1.4 percent of towns with populations less than 10,000 and 0.1 percent of towns with populations less than 2,500 had Regional Bell Operating Company-provided DSL service.¹¹ Cable modem service is similarly sparse in rural areas: less than 5 percent of areas with populations between 5,000 and 10,000 and less than 1 percent in areas with populations under 2,500 have access to cable Internet service.¹² Providers in geographically isolated areas must have a viable method for sharing information over great distances. With low rates of high-speed Internet capabilities, even considering HIT in rural communities is very difficult. Although more recent data on rural/urban connectivity is not available at this time, the Committee argues that there is no reason to believe that there have been significant changes to the rural/urban gap.

Reducing the risk of EHR adoption requires putting infrastructure in place, which makes a transition to any type of HIT appealing for a rural provider. This includes training in the new technologies and assistance for the change in clinical workflow, as well as building trust between clinicians and patients. In addition, the

technology must move beyond a *record* to include decision-support tools that will increase the quality of patient care in order for it to be truly appealing for rural clinicians and patients alike.

Even once a rural provider has made a business case for the technology and is ready to adopt EHRs, there is concern among rural providers about ensuring the availability of an honest broker when it comes to vendor selection. Larger health systems have the benefit of vendors vying for their business because of their already integrated health systems, while rural providers that are ready to adopt HIT are often left alone when deciding where to buy the technology. Slow adoption in rural areas may be related to the reality that some vendors are not yet at a point where they are willing to work with rural providers. Research has already shown that there is “an association between IT use and larger, more urban physician practices...The leaders in EHR system implementation have tended to be integrated delivery systems...”¹³ In addition, for providers that can barely afford to make the initial investment in HIT, the long-term costs associated with maintenance and technical assistance to maximize usability may require greater financial and human resources that will be difficult to find in solo practices. Given these additional costs as well as the apparent success of integrated health systems, the ability of isolated providers to work together in networking arrangements might help spread the costs of EHR adoption and the associated post-installation technical support more evenly and affordably for rural providers.

Goal Two: Interconnect Clinicians

To accomplish the goal of interconnecting clinicians in order to exchange health information, the Framework for Strategic Action presents the following strategies: foster regional collaborations, develop a national health information network and coordinate Federal health information systems.¹⁴ The concept of interconnecting clinicians is especially pertinent for rural communities; the distance between providers, heightened use of referrals and the connections rural providers have to other health systems regionally all contribute to the great need for interoperability within and across regions.

Community Impact of HIT

In Mountain City, Tennessee, Mountain States Health Alliance brought HIT to the local critical access hospital that, in turn, also brought a T1 Internet line to the entire town. This allowed the local government to update its web site with more interactive tourist features and helped local businesses update their business practices.

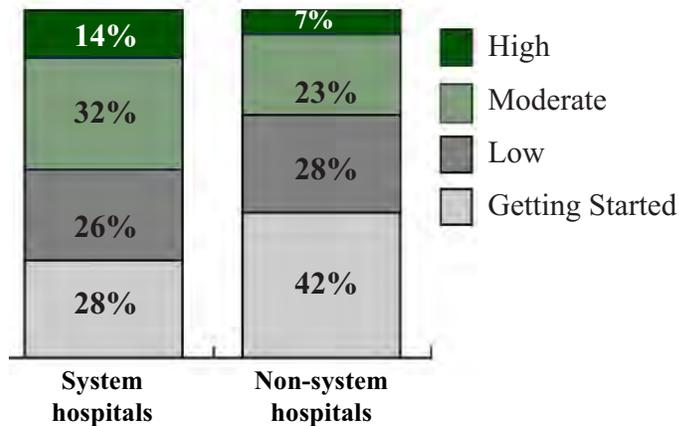
While the concept of Regional Health Information Organizations (RHIOs) is not new, there has been an accelerated push to form RHIOs across the country in an effort to connect providers and develop HIT in reaction to the Strategic Framework. Dr. Brailer explains the purpose of these organizations “...a Rio [sic] is a term that has been given to describe the coming together of community leaders, physicians, hospitals and consumers around creating a capacity to share and protect health information.”¹⁵ RHIOs are being discussed in rural areas, but many of these organizations are still in the planning process.

The Committee has found that RHIOs in their current form exist more as a concept than as an actual entity that has the ability to provide cost-effective interoperability for regions. There is a clear disconnect between the long-term promise of RHIOs and the current reality of how these organizations function. For some rural providers, more informal collaboration has the ability to narrow the resource gap.

Fostering collaborations is an important piece in the rural HIT puzzle, but oftentimes regional collaborations become metropolitan hub-centered projects and rural providers can be left out of the mix. In these situations there is concern that the rural voice will not be heard in the decision-making process and that technology may not trickle out to rural areas. Another issue with RHIOs is that they may be developed within State boundaries as opposed to regionally across States. For rural communities at the intersection of multiple States, this is particularly problematic as it runs the risk of setting up structures that go against normal referral patterns.

Hospitals that are members of systems use more IT than those that are not

Level of use of fully implemented IT systems, by system status



Source: *Forward Momentum: Hospital Use of Information Technology*. American Hospital Association, p. 6. <http://www.ahapolicyforum.org/ahapolicyforum/resources/content/FINALNonEmbITSurvey105.pdf>.

Another concern for rural providers that would like to form regional collaborations is the influence of larger health systems. If the dominant health system is developing HIT and the rural provider is not part of that system, buy-in will be difficult. In addition, if there are competing health systems in the same area developing HIT, there is concern that patient data will not be transferable across providers. The proprietary nature of vendor technology makes it likely that providers not connected to a larger system will be left behind, as well as providers connected with systems not developing HIT. Independently run health providers must be involved with the HIT development process in order to truly form regional collaborations that will interconnect clinicians. The American Hospital Association study found that 45 percent of system-affiliated hospitals have high or moderate level of use of fully implemented HIT systems as opposed to 30 percent of non-system hospitals.¹⁶ For many urban providers, larger health systems appear to be taking on the function of a RHIO in terms of health information exchange and interoperability.

Although not enough research has been done on the impact of larger health systems on all types of rural providers, these concerns nevertheless highlight the

need for some form of collaboration at the local level. Cooperative buying between rural providers has the ability to reduce costs, but will also help to ensure interoperability among providers.

For small rural communities the investment in the infrastructure needed for HIT can positively change the dynamic of the entire community. However, there is also concern that “the participating hospitals will use the network to coordinate prices and market strategies in ways that are anti-competitive, which drives up costs and ultimately hurts the consumer/patient by reducing access to care.”¹⁷ For rural communities, the following questions arise when health systems and RHIOs become involved with HIT investment: who is investing, who is going to pay and who will benefit?

While the development of a National Health Information Network (NHIN) as well as the coordination of Federal health information systems do not necessarily have specific geographic implications, it is important to note that concerns over interoperability and privacy exist for rural providers as well. One of the reasons rural areas are “behind” on HIT adoption is because rural communities cannot afford to invest in the wrong systems the first time. As a result, providers are waiting for best practices to become more readily available and for more of a national mandate for standards to be formulated before making the leap into EHR adoption. Some rural providers that have made the investment in HIT are already struggling with non-interoperable systems.

During the summer of 2005, ONCHIT released the results of a request for information (RFI) on what a NHIN will look like. Included in this RFI was the following question about the effect on rural providers: “How could a NHIN be established so that it will be utilized in the delivery of care by health care providers, regardless of their size and location, and also achieve enough national coverage to ensure that lower income rural and urban areas could be sufficiently

Johnson County Health Center: Tennessee

During a meeting in Johnson City, Tennessee in June of 2005, the Committee visited the Johnson County Health Center (JCHC) in Mountain City, Tennessee to see firsthand the impact of health information technology in rural America. JCHC is a two-bed critical access hospital.

JCHC was able to obtain various types of health technology due to its affiliation with Mountain States Health Alliance, a local health care system based in Johnson City. The center currently uses the Pixis system for its pharmacy, which allows nurses to dispense drugs. In addition, JCHC has a tracking board: a plasma screen linked with six facilities within the Mountain States Health Alliance that is also connected to the Web, which is designed to give patients real-time information about the wait time and status of patients in the emergency room. By January of 2006, the health center will be equipped with computers on wheels (COWs) in each room as well as bar coding technology that will track when the patient was treated, by whom, and what services were administered. All of these technologies were made possible by the Mountain States Health Alliance.

JCHC can also connect into the Veteran's Administration VistA system where patient labs, x-rays, EKG's, clinical reminders about the patient's age, gender and smoking habits, as well as the patient's compliance rate with previous recommendations can be accessed. However, because JCHC does not have

the same technology as the VA hospital, patient data from JCHC may not be entered into the VistA system from JCHC. Notes about the patient are recorded in a virtual notebook on the patient record which may or may not be seen by the next clinician treating the patient.

JCHC serves as a powerful example of the struggles rural providers face in keeping up with HIT. Without MSHA, this center would not have any technology and would not be located in a newer and more technologically updated facility. However, because of their affiliation with a health system that is different than the larger hospital in Johnson City, the technologies are not interoperable.

The demonstration at the Johnson County Health Clinic left the Committee asking the following questions about rural HIT:

- What impact does being affiliated with a larger health system have on rural hospitals?
- Would HIT be possible for rural providers absent a larger health system?
- What are the implications of the lack of interoperability between the VistA system and private health information systems?
- Is there potential for this lack of interoperability to create medical errors?

served?"¹⁸ Many of the responses to this question offered an affirmation of the need to consider rural and underserved areas. Others, however, offered more concrete recommendations. For example, one response recommended the following action: "Specialized support centers or 'help desks' familiar with the particular concerns of underserved and rural communities should provide support for them. Public and/or private financial support should be available for these centers."¹⁹ While specialized support centers may not be the most realistic for rural communities given the diversity of

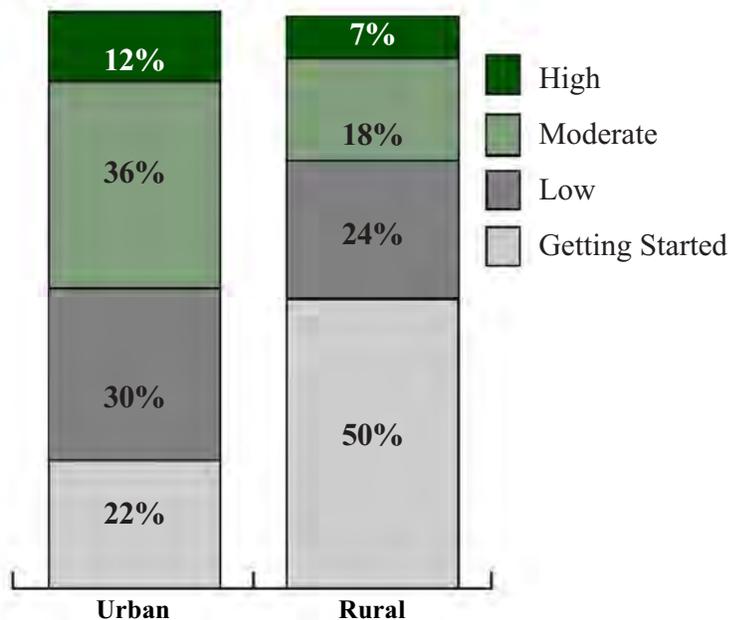
technology available, a more rural-focused HIT help desk may be useful for those seeking assistance.

Goal 3: Personalize Care

The Strategic Framework suggests the following strategies for achieving personalized care through the use of EHRs: encourage use of personal health records (PHRs), enhance informed consumer choice and promote use of telehealth systems.²⁰ Overall, the Committee believes the use of PHRs has the ability to im-

Urban hospitals use more IT than rural hospitals

Level of use of fully implemented IT systems, by location



Source: *Forward Momentum: Hospital Use of Information Technology*. American Hospital Association. Page 6. <http://www.ahapolicyforum.org/ahapolicyforum/resources/content/FINALNonEmbITSurvey105.pdf>.

prove patient care and quality. The main rural concern with each of these strategies, however, is the presumption of existing infrastructure not only with rural providers, but rural health consumers as well. Many pilot projects are testing the use of PHRs through demonstrations via the Internet and through personal home computers. While increasing consumer choice through more publicly available clinician assessments is an important goal, not everyone has the same access to this type of information.

Rural access to the Internet has been on the rise, but still lags behind urban and suburban usage. According to a recent survey of Internet use, 52 percent of rural residents use the Internet compared to 67 percent of urban residents.²¹ Only 17 percent of rural seniors use the Internet and rural seniors comprise 6 percent of all Internet users. Also relevant from this survey is the fact that 50 percent of rural residents have mixed feelings about computers and technology. These numbers identify some of the difficulties in promoting personalized care through PHRs as well as the promotion of

consumer choice through Internet-based means. However, these data also suggest that the use of PHRs may not be that far off for rural residents.

The strategy of using telehealth systems has been utilized by rural communities in recent years due to the increased availability of Federal grants to implement these systems. However, far more advanced telehealth systems such as digital imaging, high-speed Internet capabilities and advanced digital technologies are needed for implementation.²² Many telehealth technologies require training in order to operate the systems, and not all providers have the proper staff support to use this technology. Reimbursement concerns also arise in discussions of telehealth, particularly for use of telephone consultation. In addition, once an initial telehealth investment has been made, it is often difficult to sustain the systems

without proper technical assistance.

Goal 4: Improve Population Health

The following strategies have been proposed to achieve the goal of improving population health: unify public health surveillance architectures, streamline quality and health status monitoring, and accelerate research and dissemination of evidence. In order to improve population health, it is necessary for a critical mass in the community of providers to be connected. HIT has the unique ability to level the playing field in public health surveillance, but only if everyone is able to tap into the same systems. In addition, these systems must be efficient and easy to use in a busy clinical setting.

Unifying public health surveillance architecture is especially important for rural communities without local governmental public health agencies charged with the collection of public health data. Enhancing the ability of local providers to seamlessly collect and report this information has the potential to improve disease

reporting in rural areas that have traditionally struggled with public health disease surveillance due to the combination of small populations and inconsistent reporting. In implementing this strategy, it is important to note the different types of architecture currently in place to monitor public health that fall outside of large State offices or metropolitan hubs.

Streamlining quality and health status monitoring is especially important for rural communities given the burden of chronic disease and lack of local data to track key indicators of disease. Additionally, HIT enables rural providers to conduct syndromic surveillance using real-time information about emerging health threats more effectively and to use that information more rapidly than the status quo. The economic impact of reducing chronic disease and building healthier communities is also important for rural communities. Healthy communities help to expand the economic opportunities of rural areas. For example, during the site visit to Tennessee, the Committee heard testimony from one local health care leader that a prominent employer in the area noted, "...if he had known how unhealthy Johnson City was several years ago, he probably wouldn't have moved his company here."²³ In addition to quality, the use of research and dissemination of evidence can be of use to rural communities as an advocacy tool for communities in need of public health infrastructure. One means of achieving the goal of improved health status monitoring is through creating a computerized immunization registry. This is just one example of a small step that not only rural providers can take towards quality in health care.

General Rural Concerns

In addition to basic IT infrastructure concerns as well as costs of adoption, there are a number of other concerns specific to rural areas that make the phases of adoption different than for urban/suburban areas. Rural health systems are not just smaller versions of urban systems but instead have special concerns aside from size alone when considering HIT adoption and then maintaining those systems.

The issue of technical assistance and IT support is heightened for small rural providers. While many larger providers in urban areas have IT departments in-house

Wyoming Site Visit

During a site visit to Jackson, Wyoming, the National Advisory Committee had the opportunity to learn about the process of investing in HIT in a rural setting. The Committee heard from Dave Witton, Director of Information Systems at St. John's Medical Center (SJMC). This facility is unique in that they were able to hire an IT specialist to walk SJMC through the process of adopting HIT.

SJMC was faced with a number of human service challenges as well as technical challenges in the process of making their HIT decisions. One of the major struggles Witton faced when thinking about updating the facility's legacy systems was clinician acceptance and retraining. Witton emphasized that in the process of purchasing HIT, providers need to be prepared to constantly be training staff and making investments with little changes in infrastructure or internal resources. At St. John's, Witton was able to adapt to the local circumstances and work with the clinicians to be able to make the investment successful.

On the technical side, St. John's previously had a number of different legacy systems for each of the hospital's various functions that needed to be integrated with a common code set and user interface. This required the purchase of new technology from a vendor that would be able to accommodate all of the facility's technology needs. Witton developed a baseline of the interfaces and types of technology that St. John's was looking for and then used that template to choose a vendor that would meet the hospital's needs.

After visiting SJMC it is clear to the Committee that having a talented IT specialist working in-house to make the investments and work with clinicians will facilitate the success of HIT purchase and execution. The strategic HIT leadership found at St. John's could be a challenge in many rural communities, but certainly serves as a model of what may be possible in the future.

to help with technology problems, small providers in rural areas often do not have in-house IT support. For those rural providers that do, the scale and scope of this support may not compare to those in larger communities. In addition to this, workforce changes are a concern for any provider considering HIT. For rural providers with doctors who only practice certain days of the week, the extra time needed to learn the systems and the initial lag time in the efficiency of the systems make buy-in even more difficult. Without an IT department, clinicians and hospital administrators are forced to deal with problems as they arise, thus taking them away from everyday duties. There are also a number of attitudinal barriers on the part of clinicians. There are still rural providers that are operating on outdated systems and clinicians who refuse to use computers.

Cost is a factor for anyone considering HIT, but the maintenance costs for rural providers can exceed those of larger, integrated systems. Systems break down and without on-site technical assistance, the day-to-day operations of rural health systems will be affected (with potential economic impact). For example, a recent study on community hospitals found that 66 percent of rural providers believe that the initial costs are a significant barrier to adoption compared to 52 percent of urban hospitals, and that 38 percent of rural hospitals found the ongoing costs of HIT adoption to be a significant barrier compared to 27 percent of urban hospitals.²⁴

For rural providers where the community is an integral part of the decision-making process, community attitudes may play a role in deciding whether to adopt HIT. Although privacy is a general concern throughout the United States, the Committee learned from a site visit in Wyoming that some rural communities express heightened trepidation in dealing with government. Patients worry about privacy, losing the personal connection with their clinicians and increased health care costs due to the purchase of expensive IT systems.

Rural Strengths

Although there are many barriers to adoption in rural communities, rural providers have a number of advantages over urban/suburban providers that make them uniquely suited to adopt HIT. Rural health systems are

less complex than their urban/suburban counterparts. Practices are much smaller, with more focus on primary care than specialists. This makes interoperability among providers much easier than in larger systems with many different departments from many different disciplines and sectors of the health care world. Because rural communities tend to be small, they are able to bring all the stakeholders to the table to make collective decisions on HIT. Although it is possible to have competing health systems within rural communities, there is still a sense of a network among providers that makes the decision-making process more community oriented.

Many HIT circles talk about the need for a “clinician champion” who will drive the local movement towards HIT. In small rural communities the smaller size of practices as well as the history of the provider’s impact in the community may make it easier for a clinician champion to rally support within the practice for new HIT systems. A strong leader within the practice may have the ability to work more quickly in a rural facility than larger urban facilities because of fewer stakeholders as well as established community recognition.

Despite all of these strengths within individual practices, the Committee still emphasizes the need for a regional link to alleviate some of the costs and concerns with adoption.

Current HHS and Governmental Role

Given President Bush’s ambitious goal of connecting most Americans to EHRs by the year 2014, as well as ONCHIT’s comprehensive Framework for Strategic Action, HHS has created a number of Federal grants and programs to facilitate the adoption of EHRs and other forms of HIT. However, very few of these programs focus specifically on rural communities. In this section the Committee chose to highlight the few programs related to rural HIT funded by HHS as well as other Federal departments. Additionally the Office of the National Coordinator provides a comprehensive listing of all HHS-funded HIT programs.²⁵ While there are opportunities for funding available, it is important

to note that there will likely never be enough Federal funding to meet the great need for both start-up and maintenance costs incurred by investing in HIT. A National Health Information Network alone will cost \$156 billion in initial capital investments during the first five years.²⁶ In that regard, this transition is not unlike the move to electronic billing for health care providers in the 1990s. Eventually, it was seen as an ongoing cost of doing business. To the extent that public and private payers start demanding some level of EHR adoption or standard base of HIT investment, providers will have no choice but to adapt.

HHS Programs: Rural-Specific HIT

Agency for Healthcare Quality and Research (AHRQ)

In September of 2004, AHRQ began an effort to promote the use of HIT through two grant programs. First, AHRQ provides competitive grants for the development of State and regional networks linking clinical information. Five States were chosen for these projects designed to enable States to build information networks: Colorado, Indiana, Rhode Island, Tennessee and Utah. In addition, AHRQ provides planning, implementation and demonstration grants for HIT projects designed to focus on rural and underserved areas. AHRQ is devoting \$96 million over three years in grants for small and rural hospitals and communities.²⁷ AHRQ also funded a project to launch the AHRQ Resource Center for National Health Information Technology. This resource center provides technical assistance to AHRQ grantees as well as other Federal partners as they move forward with HIT projects.²⁸

Federal Office of Rural Health Policy

ORHP administers a number of grant programs for rural providers that have been utilized for HIT. For example, funds from the Small Rural Hospital Improvement Grant Program (SHIP) and the Rural Hospital Flexibility Grant Program have been used to purchase HIT infrastructure as well as improve hospital quality through HIT applications. A survey done in 2004 of SHIP recipients indicated that 72 percent of grantees have used SHIP dollars for HIT.²⁹ These were low-

cost HIT projects, as opposed to system-wide HIT activities. In addition to SHIP, Rural Health Network Development grants have been used to develop HIT infrastructure by providing funds for the purchase of hardware, software and technical assistance, with the goal of creating an integrated health network. The implementation of shared information management systems, telemedicine capabilities and prescription assistance software programs has strengthened rural health care systems by connecting providers more effectively to each other and to their patients.

HHS Programs: General HIT

Office of the National Coordinator for Health Information Technology (ONCHIT)

The purpose of ONCHIT is to implement President Bush's plan for EHRs by the year 2014. The work of ONCHIT does not have a geographical focus, but because their work is broad, it has rural implications.

VistA-Office EHR

The Veterans Health Administration was one of the first health providers to utilize EHRs for its five million veterans through the VistA system. An adapted product called VistA-Office EHR was to be released for public use in August of 2005, but at the publication date of this report, the final product has not been made available. Instead, an evaluation version of this product was made available in October of 2005. For almost a year VistA-Office EHR has been presented as a potentially cost-saving program for private practices that lack the resources for private purchasing of an EHR system. The Committee has found, however, that the problems surrounding the release of the product, lack of technical support and high cost of licensing are making this system less available for rural communities than originally thought. Please see the Recommendations section for the Committee's recommendation on the release of this software.

In addition to the Strategic Framework outlined earlier in this chapter, ONCHIT is committing \$4 billion for HIT projects across America. To date, ONCHIT has created a number of programs to coordinate HIT efforts. First, the American Health Information Community (AHIC) has been created to provide public and private input and recommendations for standards and interoperability of EHRs. In addition, during June of 2005, Secretary Leavitt announced four requests for proposals (RFPs) for contracts designed to achieve interoperability. Once announced, these contractors will work closely with AHIC on issues such as standards, certification and interoperability. ONCHIT also issued a request for information (RFI) regarding the formation of a National Health Information Network. Included in this RFI were questions regarding the implications of a larger HIT network on rural and underserved communities.

National Library of Medicine (NLM)

NLM administers a number of grants aimed at the use of various types of HIT. In particular, Integrated Advanced Information Management Systems (IAIMS) Grants provide funding for integrated HIT systems and the Office for High Performance Computing and Communications offers a number of grants to facilitate communication between networks. NLM also administers grants for the purpose of research and development of various technologies. Also within NLM, the Commission on Systemic Interoperability was established to “develop a comprehensive strategy for the adoption and implementation of health care information technology standards that includes a timeline and prioritization for such adoption and implementation.”³⁰

Centers for Medicare and Medicaid Services (CMS)

CMS, through statewide Quality Improvement Organizations (QIOs) administers the Doctor’s Office Quality – Information Technology (DOQ-IT) program to promote the use of EHRs. This program provides technical assistance to small- to medium-sized practices in the planning and implementation of EHRs. In particular, DOQ-IT is designed to assist small primary care providers in making workflow more efficient

through EHRs and also help prepare providers for the office changes needed to make EHRs more feasible. In addition, CMS is releasing the VistA-Office EHR product at a low cost for providers across the United States.

Office for the Advancement of Telehealth (OAT)

The Telehealth Network Grant Program provides funding for the improvement and establishment of sustainable telehealth programs in medically underserved areas including urban, rural and frontier communities.³¹ Additionally, in 2004, OAT partnered with the eHealth Initiative to create the Connecting Communities for Better Health Resource Center to help facilitate Web-based information exchange on HIT issues.³² The resource center contains a searchable database of HIT projects being implemented across the United States. Grants are also available through the Connecting Communities for Better Health grant program for local health information exchange projects. Of the original nine grants, CareSpark of Tennessee was the only project focused specifically on connecting rural communities through HIT. In 2005, approximately \$30 million was earmarked for urban and rural HIT projects. This is worth noting because it represents a substantial investment in HIT-related activities and a significant portion of that funding is for projects in rural areas.

Other Federal Initiatives

In addition to HHS-funded programs, other departments in the Federal government are working to help rural Americans gain access to technological infrastructure and to HIT. Through a Congressional and Federal Communications Commission allocation of funding, the Universal Service Administrative Company administers the Universal Service Fund grants program to provide funding to rural providers for discount rates on installation and implementation of telecommunications technology.³³ Other rural HIT opportunities include the U.S. Department of Agriculture’s Community Connect Grant Program, which provides financial assistance for broadband

Revolving Loan Program for EHR Adoption

Given the limited amount of Federal funding available for EHR implementation, the West Virginia Rural Health Infrastructure Loan Fund updated its loan program to include financing for rural EHR purchases. While traditionally the rural health care community has discussed financing for the building of actual facilities, now HIT is becoming a part of rural health care capital discussions. The Loan Fund is part of the Robert Wood Johnson Foundation's Southern Rural Access program.

service to rural communities,³⁴ as well as the Distance Learning and Telemedicine grant, which provides funding for advanced technology in rural and/or economically disadvantaged communities.³⁵

While it is clear that equity in HIT adoption is a priority for HHS as well as the Office of the National Coordinator, it is not clear that Federal dollars are making their way to rural communities. Some Federal attention has been paid to assist rural providers in planning and implementing HIT projects through AHRQ and through some ORHP grants; however, the majority of Federal HIT demonstrations have focused on urban and suburban health systems.

Many Federal programs fail to factor in the unique circumstances of rural America. Federal grant program managers cannot assume that dollars flowing to urban health providers will trickle out to rural communities. Similarly, RHIO structures that focus on an urban hub with suburban spokes to a rural rim do not guarantee full rural participation and benefits in a regional information exchange. In addition, expansion of the infrastructure needed to even adopt HIT in rural communities has not been strongly supported by Federal programs. For example, there is still a need to close the gap between urban and rural areas in Internet connectivity and computer use.

Conclusion

As ONCHIT and the rest of the Department of Health and Human Services move forward in executing the President's goal of connecting most Americans to an EHR by 2014, the Committee hopes that the special considerations of rural Americans are factored into the decision-making process.

This chapter has highlighted a number of challenges rural providers face in adopting HIT at each phase of ONCHIT's four goals, which include limited access to capital and infrastructure to adopt HIT, and lack of workforce expertise and difficulty in obtaining community buy-in, among other major concerns. The Committee has also brought attention to a number of strengths rural communities possess that make them uniquely suited to adopt HIT including the increased opportunity for a clinician champion and heightened ability to link up with other rural providers to create regional networks.

The Committee recognizes the opportunities HIT has for providers regardless of size or location and hopes that this chapter has brought attention to a number of challenges and strengths rural providers possess as HIT becomes a regular part of the American health care system.

Recommendations

In order to make widespread HIT adoption a reality for rural providers, the Committee recommends the following:

Universal Service Funds:

The Secretary should work with the Congress and the Federal Communications Commission to allow the use of Universal Service Funds for rural health care providers to build greater infrastructure for broadband access in rural communities.

Advisory Groups:

The Secretary should encourage groups like the American Health Information Community to consult with the Federal Office of Rural Health Policy, HHS Office of

Intergovernmental Affairs and other key national rural health organizations about the impacts of their decision-making on rural communities.

VistA-Office EHR Software:

The Secretary should devote funding resources to ensure that technical assistance is available for rural communities after the final release and dissemination of the VistA-Office EHR software.

HIT Research Agenda:

The Secretary should commission the Agency for Health Research and Quality to conduct a study examining the costs and benefits of EHR use in rural communities to determine the disconnect between the payers and the beneficiaries of adoption. In addition, this study should examine the benefits and pitfalls of adoption for rural communities in terms of public health and syndromic surveillance reporting. This study should include data collection that allows policymakers to differentiate between rural and urban, provider size and impact of affiliation with larger integrated health systems.

Collaborative Grants:

The Secretary should use the Section 301 Demonstration authority within the Public Health Service Act to support rural HIT collaborative grants to encourage the collaborative networking model for HIT purchasing and information exchange.

HIT Performance Measures:

The Secretary should develop HIT performance measures for post-conversion critical access hospitals with a focus on HIT and quality of care.

DOQ-IT:

The Secretary should expand the eligibility for the Doctors Office Quality-Information Technology (DOQ-IT) program available through the Medicare Quality Improvement Organizations to allow assistance to rural health clinics and Federally Qualified Health Centers.

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Family Caregiver Support of the Rural Elderly

Why the Committee Chose This Topic

Families—not nursing homes, social service agencies or other formal programs—provide the most long-term care to older persons with disabilities. Over 90 percent of older people in need of assistance have a family member or friend providing care.^{1,2,3} According to AARP, more than 44 million adults provide care for a family member. The majority of these family members are caring for someone 50 or older. According to the U.S. Department of Health and Human Services' (HHS) Administration on Aging (AoA), the majority of family caregivers are female (56 percent)—daughters, daughters-in-law or spouses between the ages of 40 and 70, with the average age being 46. However, an increasing number of men are beginning to take on these responsibilities.⁴

Caregiving is a long-term commitment. Many caregivers significantly underestimate the number of years they will spend caring for a family member. Forty-six percent of caregivers expect to provide care for about two years. In reality, the average length of time they will spend in the role is eight years.⁵ They will also dedicate an average of 20 hours per week to caregiving.⁶

Two-thirds of all caregivers also work outside the home. Data from the Commonwealth Fund Biennial Health Insurance Survey reveal that nearly 16 million working-age adults are currently caring for a family member.⁷ Sixty-two percent of caregivers have had to make some kind of adjustment in their work life, such as reducing hours, taking early retirement, going from full-time to part-time work or taking unpaid leave.⁸ An estimated \$11.4 billion in lost productivity each year can be attributed to informal caregiving, according to the 1997 *MetLife Study of Employer Costs for Working Caregivers*.⁹ The study further details the annual cost of eldercare to employers, aside from lost productiv-

ity: \$4.9 billion is spent annually on replacement costs for employees who quit; \$3.7 billion is spent on work-day interruptions; and \$1 billion is spent on responding to eldercare crisis events. The American Geriatrics Society reports that one in five caregivers will quit his or her job to become a full-time (and unpaid)¹⁰ caregiver.¹¹

Nowhere is the impact of providing in-home, long-term care to loved ones greater than on the caregivers themselves. Isolation, resentment, guilt, anger and financial difficulties, in addition to missed work, all plague the caregiver. One out of three caregivers reports their own health to be fair or poor.¹² Research shows that informal caregivers suffer from high levels of stress, burnout and insomnia, and are more likely to use psychotropic drugs.¹³ However, this research does not identify differences between the stresses of rural caregivers as compared to their urban counterparts. More research on the links between caregiver stress and the consequence of compounded health outcomes must be undertaken with a rural focus.

It is estimated that 20 percent of family caregivers suffer from depression, twice the rate of the general population.¹⁴ Yet, the Family Caregiver Alliance believes this to be a low estimate and calls caregiver depression “a silent health crisis.” Studies show that even after the caregiving ends, depression may linger. An Ohio State study revealed that 41 percent of former caregivers continued to be depressed up to three years after the person they were caring for had died.¹⁵ The study also shows that women caregivers have higher rates of depression than men.¹⁶

Significant benefits to individuals and society can be accrued by offering assistance to caregivers, especially in the first weeks of caregiving. Caregiving burnout is a risk factor for the hospitalization and institutionalization of the care receiver.¹⁷ Researchers Colerick and George report in *The Gerontologist* that caregivers who utilized in-home help services earlier in their caregiving careers were more likely to delay

Robert Wood Johnson Foundation's Faith in Action

Faith-based organizations of all kinds are enthusiastically supported by local residents. The Robert Wood Johnson Foundation (RWJF) is supporting a major national program that helps communities meet the needs of the growing number of caregivers of persons who are homebound. While not necessarily focused on rural areas, the program, Faith in Action, has been embraced by rural health advocates. Since its inception in 1993, RWJF has awarded 1,091 Faith in Action grants, and in July 2000 the Foundation launched a second phase that planned to award up to 2,000 additional grants over seven years.

institutionalization of their loved one. The findings point out the practicality and cost-effectiveness of early community-based caregiver service use.¹⁸

Reimbursement mechanisms currently focus on acute episodes that are fairly predictable. Caregiving, on the other hand, is an ongoing, long-term concern that is highly individual and personal. Informal caregiving is the backbone of the American long-term care system where the value of the services provided by informal caregivers is estimated to be \$257 billion annually, two times the amount currently spent on homecare and nursing home care.¹⁹

The Committee shares the concerns of the AoA, and others, regarding the impact of family caregiving on the caregiver and considers it a serious public health and human service issue. More assistance to caregivers, especially early in their caregiving careers, is the major emphasis of this report. Because of its compassion and empathy for the caregiver, along with the recognition that government programs save billions through the free services caregivers provide, the Committee places support for the caregiver high on its list of important rural health and human service policy priorities.

Currently, almost 65 million people live in rural America, nearly 35 million of whom are elderly, defined as over age 65.²⁰ Twenty-two percent of all elderly

individuals in the nation reside in rural areas²¹ a larger proportion than in urban areas.²² In comparison to their urban peers, rural elderly are older,^{23,24} less educated, poorer,²⁵ and more likely to have chronic conditions such as arthritis, hypertension, diabetes and heart disease.²⁶ In addition, a larger proportion of the “oldest old,” those 80 years and older, reside in rural areas; 18 percent in nonmetro areas compared to 15 percent in metro areas.^{27,28,29} The older population has grown in rural areas from the influx of retirees looking for a less hectic lifestyle and the out-migration of young adults searching for employment opportunities elsewhere.

Barring accidents or other unplanned events, long-term care of some sort will eventually be required by most of us. Unfortunately, rural elderly have less access to skilled nursing and other long-term care services than elderly living in other areas of the country.³⁰ In fact, access to quality health services, in general, was identified as the top rural health priority among State and local health care leaders convened to discuss projected rural health needs in 2010.³¹ Without formal services available, rural elderly must rely even more heavily on family and friends for assistance. Policymakers would do well to consider building on the informal structures already in place in rural areas by supporting family caregiver assistance programs, such as the National Family Caregiver Support program and emphasizing the unique rural challenges for rural family caregivers.

Rural caregivers are often separated from their extended family because education and job opportunities for the younger generations are typically located elsewhere. This makes the isolated rural caregiver older than average.³² Rural caregivers are more likely to report health care problems associated with their caregiving than urban caregivers. But, they are also more likely to lack health insurance, and half of all caregivers do not seek care for themselves because of the cost.³³ In addition to the rural problems of provider shortages, lack of transportation and difficulty in accessing services, rural families are reluctant to take advantage of agency-based services because of the welfare stigma they associate with it.³⁴ Characteristically more independent, rural residents are, in general, hesitant to seek help and resist using formal services.³⁵ Rural caregivers also lack the expertise needed to co-

ordinate services, the knowledge of available services and the resources to pay for them. Furthermore, they often do not have a reliable form of transportation.³⁶

Faith-based Organizations

For many rural families, their house of worship is a real source of support and can be a useful mechanism for disseminating health service program information. Families may follow the advice, assistance and information from fellow church members before they look to local government service providers. Moreover, fellow parishioners are able to see firsthand the types of help most needed by the caregiver and his or her family. Thus, along with offering prayers for caregivers and care receivers during the weekly services, offers of assistance such as transportation, respite, help with

insurance and financial paperwork, house cleaning, meal preparation and others can be offered.³⁷

Compounding the stigmatization of accepting government agency services, often the service providers are not sensitive to the unique rural culture of the catchment area. This insensitivity may be due to the reality that the service provider is not local. These are the primary reasons that the few services that are available in rural areas for both caregivers and care receivers are often underutilized. In rural areas stoicism and autonomy are prized qualities, sometimes to the detriment of the individuals living there. Increased outreach and education, especially in faith-based settings, could diminish the stigma related to acceptance of caregiver services in rural America.

Continued on page 47

Standardization of Caregiver Programs

The requirements for a comprehensive and coordinated community-based system of care are delineated in the Older Americans Act. The Act states that any such system shall have the 10 elements listed below. These points serve as the driver for AoA programs. The Committee applauds the development of a standard set of caregiver program requirements and suggests that the Secretary reiterate the importance of using this list as the “floor” for all HCBS services:

- Have a visible focal point of contact where anyone can go or call for help, information or referral on any aging issue.
- Provide a range of options and choices.
- Assure that these options are readily accessible to all older individuals, the independent, semi-dependent and totally dependent, no matter what their income.
- Include a commitment of public, private, voluntary and personal resources devoted to supporting the system.
- Involve collaborative decision-making among public, private, voluntary, religious, and fraternal organizations and older people in the community.
- Offer special help or targeted resources for the most vulnerable older individuals, those in danger of losing their independence.
- Provide effective referral from agency to agency to assure that information or assistance is received, no matter how or where contact is made in the community.
- Evidence sufficient flexibility to respond with appropriate individualized assistance, especially for the vulnerable older person.
- Have a unique character that is tailored to the specific nature of the community.
- Be directed by leaders in the community who have the respect, capacity and authority necessary to convene all interested persons, assess needs, design solutions, track overall success, stimulate change and plan community responses for the present and for the future.

The Value of Early Screening of Caregivers

The added responsibility of caring for an older adult with a chronic illness or a disability overwhelms many caregivers who are inundated with career, child rearing and/or immediate family responsibilities. Many caregivers often neglect their own needs in order to attend to the needs of others, which can be detrimental to the physical and mental health of the caregivers and their care recipients alike.

Demonstration research completed by the University Of Maine Center on Aging, as part of the U.S. Administration on Aging-funded Maine Primary Partners in Caregiving (MPPC) project, found that the implementation of a brief screening tool into routine primary care physician (PCP) office visit procedures is an effective means of identifying caregivers who are at risk of caregiver stress and burden.¹ PCPs are also valuable referral sites to supportive community resources and information for caregivers. The participation of medical offices in the caregiver referral process lends validation to available support services tailored to caregivers and serves to increase the probability that at-risk caregivers will explore and utilize services that are available.

The MPPC project, administered by the Eastern Agency on Aging in Bangor, Maine, was designed to demonstrate that information, training, and supportive services provided to caregivers on a preemptive basis would improve the quality of life for these individuals and their families. Initial caregiver contacts tended to result in the provision of information rather than more intensive, involved interventions. Such dissemination of information proved to be an effective early intervention strategy, forestalling the need for premature and/or more expensive modes of intervention.²

Caregiver specialists were the keystone to this linkup between PCPs and caregiver information and services. The caregiver specialist made initial contact with the PCP-referred caregiver, offering the provision of information, resources and service coordination to the caregiver.³

Results of the project indicated that the exceptionally difficult work of caregiving becomes increasingly

demanding as the health of the care recipient deteriorates.⁴ It was found that increased depression scores were associated with lower levels of expressed caregiver competency and confidence, increased perceptions of caregiver burden, a greater sense of social isolation and smaller social networks.⁵ Findings also suggested that early intervention appears to reduce incidence of crises and that stress levels of caregivers can be reduced by use of the array of services offered by caregiver specialists.⁶

Caregiver screenings performed by PCPs increase the number of caregivers identified as being at-risk of compromised health resulting from compounded stress levels and overwhelming burden levels over time. PCP-initiated interventions have the capacity to improve life satisfaction/morale levels in caregivers, increase confidence and competency levels in caregivers, reduce feelings of isolation and improve the quality of family relations.⁷ Linking caregivers to social services can and should be a natural extension of the role of the PCP based on the trust and rapport families often have with the medical practitioner.

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- ² UMaine Center on Aging (2005). *Maine primary partners in caregiving: A project manual*. Orono, ME: University of Maine.
- ³ *Ibid.*
- ⁴ *Ibid.*
- ⁵ Kaye, L.W., et al. (2003). Early intervention screening.
- ⁶ There were measurable reductions of depression, stress, strain, and sense of isolation in caregivers between Time I and Time II interviews.
- ⁷ UMaine Center on Aging. (2005). *Maine primary partners in caregiving*.

(Continued from page 45)

What Is Known About Family Caregiver Support of the Rural Elderly

Data and research specific to rural caregivers is minimal. The AoA and other agencies involved in collection of data related to family caregivers do not separately identify data gathered from, and pertaining to, rural parts of the country. Moreover, the Committee is unable to truly determine and report the rural need because key Federal organizations do not evaluate programs with a uniform rural geographic standard. The lack of rural data is a Department-wide issue. In its 2002 report, *One Department Serving Rural America*, the HHS Rural Task Force described the lack of a common definition of “rural” as one of the Task Force’s three most important findings. The vague and various definitions of “rural” used by HHS agencies make it difficult to identify specifically rural needs, evaluate rural services and service impact, and quantify HHS’ investment in rural communities.³⁸

State of the States in Family Caregiver Support: A 50-State Study

Most of what we know about caregivers is from a report published by the Family Caregiver Alliance in 2004 entitled, *State of the States in Family Caregiver Support: A 50-State Study*.³⁹ The study, funded by AoA under the Federal Projects of National Significance, was an effort to better understand the scope of caregiver support programs in the States. Due to the lack of rural-specific data, this national study was used as a data source and inferences were made for rural areas given the national data. Through surveys of State program administrators representing 154 programs, the survey reveals that all States provide some caregiver support services. Most States administer these services out of the State Unit on Aging with Area Agencies on Aging (AAAs) typically operating the local programs. Indeed,

Top Five Unmet Needs of Caregivers in the States

	Program responses*	
	<i>n</i>	%**
Lack of resources to provide a range of services	69	50%
Limited respite care/options	66	47%
Lack of public awareness about caregiver issues/programs	38	27%
Shortage of providers (workforce)	23	17%
Limited access to services in rural areas	13	9%

Note. *N=139. **Percentages are based on total number of responses.

responsibility for three-fifths (62 percent) of the programs in this study is shouldered by local AAAs.

According to the findings of *State of the States in Family Caregiver Support*, most States offer respite care (95 percent); provide information and assistance (69 percent); and offer education and training opportunities (62 percent). Access to State programs is available from the AAA, toll-free numbers, other local or State agencies, and the Web.⁴⁰ Access to services, according to 53 percent of survey respondents is through the AAA, but 77 percent of respondents report that caregivers in their States do not have access to the same program services. Only 21 States report that their State AAAs offer every one of the five specified service components: information, assistance, counseling, respite and supplemental services.

More than half of State programs offer training for staff who work with family caregivers.⁴¹ The top five training areas currently offered include: caregiver assessment; best practices in service delivery; data collection and reporting; outreach and public awareness; and caregiver intake. However, 91 percent of respondents in *State of the States in Family Caregiver Support* listed best practices in service delivery, culturally/ethnically appropriate services, program evaluation/outcome measures, outreach/public awareness and caregiver assessment as areas of training most needed

Cash & Counseling

Cash & Counseling is a national program sponsored by The Robert Wood Johnson Foundation (RWJF), the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services, and the Administration on Aging. In addition, the Centers for Medicare and Medicaid Services reviews States' Section 1115* demonstration or 1915 (c) waiver (HCBS) applications and provides continuing oversight and technical assistance in the waiver process.

The Cash & Counseling approach provides consumers with a flexible monthly allowance based on an individualized budget, which allows them to direct and manage their own personal assistance services and address their own specific needs. This innovative program offers counseling and fiscal assistance to help consumers manage their allowance and responsibilities by themselves or with the aid of a

* Section 1115 of the Social Security Act provides the Secretary of Health and Human Services with broad authority to authorize experimental, pilot or demonstration project(s) which, in the judgment of the Secretary, (are) likely to assist in promoting the objectives of (the Medicaid statute).

representative. These main features are adaptable to consumers of all ages with various types of disabilities and illnesses. Cash & Counseling intends to increase consumer satisfaction, quality and efficiency in the provision of personal assistance services. The National Program Office at the Boston College Graduate School of Social Work coordinates and directs the replication project.

- Eleven States have been awarded three-year grants of up to \$250,000 to implement the Cash & Counseling model and collect information to monitor the effectiveness of these programs.
- Cash & Counseling grants were awarded in October 2004. Each State has been awarded one three-year grant.
- Two States with ambitious plans to expand significantly beyond the basic Cash & Counseling model may be eligible for an additional \$100,000 over the same three-year period. All grants will be awarded in summer 2004.

For more information on Cash and Counseling, see <http://www.cashandcounseling.org/>.

by staff, despite the fact that these training areas are already offered in most programs.

The *State of the States in Family Caregiver Support* study makes clear that States are hungry for information and examples of successes from other programs that serve elderly caregivers. *Rural Healthy People 2010* cites innovation, measurement and assessment, and the ability to be replicated across rural settings as the elements upon which a rural health or human service program should be monitored for best practices.

Despite the recognition that culturally appropriate services and program evaluations are beneficial training components, these are not among the actual training programs most often offered.⁴² During its site visits, the Committee recognized the need to strengthen culturally sensitive program training for people who deliver family caregiver support services, especially in

the area of outreach.

Unmet Needs

State of the States in Family Caregiver Support also uncovered the top five unmet needs in States for caregiver support. Half of the respondents reported lack of resources to provide the range of services required under the National Family Caregiver Support Program, followed closely by limited availability of respite care. Lack of public awareness about caregiver issues/programs, shortage of providers and limited access to services in rural areas⁴³ round out the top five needs list. These areas represent the primary focus of the Committee's report.

Continued on page 50

Mobile Day Care

(Source: *Alzheimer's Resource Room, Successful Delivery Strategies. HHS, AoA*)

One successful caregiver service delivery strategy is mobile day care, an area pioneered by the State of Georgia. The State, along with the Atlanta Alzheimer's Association and the Georgia Division of Aging Services, brings social day care to rural communities that do not have the resources to create and staff their own full-time program. The centers are usually open one or two days per week, for six hours a day and held in a community building (church, senior center, etc.) in the rural community. By sharing staff and resources among several communities, the caregivers in each community benefit from this unique respite service.

As in the *State of the States in Family Caregiver Support: A 50-State Study*, the need for respite services for Georgia's rural caregivers was identified by State service agencies as a critical need.

How to Develop a Mobile Day Care Program

The three primary tasks required to develop a mobile day care program are hiring staff, identifying an appropriate location and making arrangements for client transportation and meals. The staff should be hired from the local community, if possible. The responsibilities of the staff in various positions include: developing a coalition of community professionals and caregivers to assist in promoting the mobile day care; developing program activities; nursing; and case management.

Arrangements for a day care location, transportation and meals must be made. An appropriate facility must provide adequate, part-time, safe space for persons with dementia. In Georgia, churches and senior centers have been used.

Transportation for day care participants is also an issue. In one Georgia county the local aide rides in the Senior Services van to pick up clients for the mobile day care program. Meals need to be coordinated. One Georgia site was located in a senior

center that provided the meals on-site, which reduced the cost of meals. Meals on Wheels is another resource for mobile day care meals.

Barriers and Obstacles

The mobile day care program had to address several community concerns. When negotiating with the host organization about space, liability issues were a concern. Additionally, the comfort of other groups using the shared space with a dementia population needed to be accommodated through education. The community coalition was helpful in guiding the project's outreach and education efforts to assure compatibility with rural culture tenets of "taking care of our own." Transportation remains a key element in rural family participation in the mobile day care program. Other challenges still require resolution at the State level. For example, if Medicaid patients participate in mobile day care, they lose "home-bound" status.

Benefits of Mobile Day Care

- Respite is now available in rural communities that previously had no dementia services, at a minimal cost.
- Staff capacity is strengthened by integrating the staff with other existing programs within the State.
- Because program aides are hired from the local communities as much as possible, clients know the staff member. In Georgia, this made trying the program easier for families and clients.
- The community coalition brings together individuals and agencies that have not previously worked together.

For more information about the Georgia program see http://www.aoa.gov/alz/media/pdf/mobile_pdf.PDF.

(Continued from page 48)

1. Lack of Resources

Of all the challenges faced by the States in providing services to family caregivers, inadequate funding is ranked first by 64 percent of respondents of the *State of the States in Family Caregiver Support* study. A mix of public and private funds finance caregiver support services in all States. The four main sources of funding include State funds, AoA National Family Caregiver Support Program funds,⁴⁴ Medicaid waivers and private donations. Each of these funding streams allows State flexibility in expending funds based on local needs. Unfortunately, this same flexibility makes it difficult to collect spending data in a way that is comparable across States. State general revenues are relied on by 57 percent of programs in *State of the States in Family Caregiver Support*.⁴⁵

Most States pay families to provide care in at least one of their State programs. However, this occurs more frequently through the Medicaid waiver program than through NFCSP or State programs. The NFCSP funds caregiver services in 37 percent of programs.⁴⁶ This innovative program is propelling the needs of caregivers to the fore but is inadequately funded (\$138.7 million in 2003). As a result, States must fall back on general revenues, Home and Community-based waivers and Aged/Disabled Medicaid waivers to fill funding gaps. For people living in rural America, health care and social service programs not only provide needed services, they also represent a significant segment of the local economies. These programs, however, frequently lack adequate funds, personnel and support networks.⁴⁷

The aged and disabled Medicaid waivers finance care management, health, in-home services and caregiver respite for family caregivers of Medicaid waiver beneficiaries in 33 percent of State programs.⁴⁸ However, when Medicaid covers caregiver services, it is often an optional service rather than a mandatory one. Because optional services are not deemed essential, they are the first ones to be cut. This puts the availability of services in jeopardy during times of restricted State budgets. The Commonwealth Fund advocates increases in the Medicaid and Medicare programs to address car-

egivers' access to health care for themselves. Eligibility of caregivers for one of these programs would ease the financial burden of caregiving for those without health insurance.

Funding for family caregiver support is being addressed in other innovative ways. One of the best examples is the Cash & Counseling program, a national program sponsored by The Robert Wood Johnson Foundation (RWJF), the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the United States Department of Health and Human Services and the Administration on Aging (AoA). The Cash & Counseling approach provides consumers with a flexible monthly allowance that is based on an individualized budget, allowing them to direct and manage their own personal assistance services and address their own specific needs. Twelve States have been awarded three-year grants of up to \$250,000 to implement the Cash & Counseling model and collect information to monitor the effectiveness of these programs: Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington and West Virginia. Illinois has also obtained funding by the Retirement Research Foundation to implement an independent Cash & Counseling program.

Expanding Medicaid Home and Community Based Services (HCBS) waivers, integrating long-term care services, and implementing or expanding consumer-directed care are the top long-term care issues identified by the States in *State of the States in Family Caregiver Support*. The Committee strongly encourages consumer-driven approaches such as the Cash & Counseling model for rural elderly caregiver support. In addition to allowing the clients to determine what their biggest needs are, consumer-driven approaches may alleviate the stigma rural elderly and their families associate with receiving care from outside organizations.

2. Respite⁴⁹

Ninety-five percent of caregiver programs offer some type of respite service.⁵⁰ Even so, respite is one of the top five unmet needs identified in *State of the States in Family Caregiver Support*. Caregivers are on duty 24-hours a day, every day of the week. They choose to care for their loved ones in the safety of their own home,

rather than see their loved ones institutionalized. But the strains of being responsible for a chronically ill older person or one with disabilities are enormous. The impact is both physical and mental. Some nine million caregivers have health problems of their own.⁵¹ Respite care and support groups can help caregivers keep their loved ones at home longer and can alleviate caregiver depression and other negative effects of serving as a caregiver.^{52,53} A healthy caregiver can prevent the premature institutionalization of the family member receiving care.

The table below, “Respite Expenditures Under Medicaid,” reports participants (Part) and expenditures (Exp) for respite services provided under all Medicaid 1915(c) waivers, by eight target groups, for 2001 and 2002 with percent change (2001-02). Respite is defined differently in waivers from State to State. The figures below arise from a broad definition of respite that includes services variously titled: respite, respite/caregiver or family supports/family education. This represents all caregiver support provided under the waiver program, which dwarfs the modest level of total NFCSP funding to the states (\$138.7 million in 2003).

3. Lack of Awareness of Caregiver Issues/Programs

State of the States in Family Caregiver Support found that the public is generally unaware of the challenges faced by caregivers or of the local services and opportunities available to caregivers. Results from the study reveal that lack of information and outreach to the public is of great concern to State program administrators. Almost half of the respondents (46 percent) feel that many families who might benefit from their services do not know where to go for help.⁵⁴

The study also confirmed that caregivers themselves often do not identify with the term “caregiver,”⁵⁵ an issue that was also addressed in a 2002 report by the National Family Caregiver Association and the National Alliance for Caregiving entitled *Self Awareness in Family Caregiving*. The findings in this report were based on a nationwide survey of family caregivers conducted by AARP in 2001 that sought to determine whether the term “caregiver” was one with which family caregivers identified and whether they sought the types of assistance⁵⁶ that would indicate their acknowledgement of the role. The survey results indicated that “identifying oneself as a ‘caregiver’ was the most significant

Respite Expenditures Under Medicaid

Respite service in waivers by target groups, 2001 and 2002

	Part	Exp	Part	01-02 % change	Exp	01-02 % change
MR/DD	46,817	\$180,691,009	52,411	11.95%	\$189,201,180	4.71%
Aged	9,744	\$32,416,619	10,879	11.65%	\$40,619,553	25.30%
Aged/Disabled	21,443	\$53,609,694	22,091	3.02%	\$55,844,027	4.17%
Disabled	714	\$3,378,673	966	35.29%	\$5,028,139	48.82%
Children	3,409	\$23,649,070	3,451	1.23%	\$24,051,295	1.70%
AIDS	30	\$98,939	18	-40.00%	\$22,728	-77.03%
Mental Health	273	\$1,407,176	272	-0.37%	\$1,006,196	-28.50%
TBI/SCI	226	\$1,238,574	391	73.01%	\$1,753,978	41.61%
Total Respite	82,656	296,489,754	90,479	9.46%	\$317,527,096	7.10%

Source: Department of Social & Behavioral Sciences, University of California San Francisco.

variable in determining to what extent a respondent took the self-help or self-advocacy actions.”⁵⁷ Remarkably, the age of caregiver, age of recipient, gender, race and/or ethnicity, marital status, household income and employment status were not significant factors. Because caregivers themselves often do not recognize their role as such, they do not search out programs that could offer assistance.

The Committee feels strongly that outreach efforts to educate families and communities about caregiver needs and available local services are critically important, especially early in the family caregiving career. In addition, the terminology used in the outreach approaches/methods must be very clear and straightforward so that all caregivers recognize themselves.

4. Shortage of Providers/Workforce

The Committee addressed the inadequacies of the rural health care infrastructure, including workforce issues, in its *2004 Report to the Secretary*. While 20 percent of the population lives in rural areas, only 10 percent of all physicians practice in these areas.⁵⁸ Recruitment and retention of providers to rural areas is difficult for many reasons including lower salaries, outdated equipment, scope of practice strains, geographic isolation and limited continuing education opportunities.

The Family Caregiver Alliance’s *State of the States in Family Caregiver Support* finds that more than one in three state program administrators (36 percent) face a shortage of qualified service providers (e.g., social workers) or direct care workers (e.g., nurses aides).⁵⁹ Without a cadre of regular providers rural communities face elevated infant and childhood illness and mortality rates, over-utilization of emergency rooms and hospitalization rates for preventable conditions that are significantly higher than the national average.⁶⁰

5. Limited Access to Services

The availability of a range of caregiver services is a problem within States and across the nation. Seventy-seven percent of State program administrators report that caregivers in their State do not have access to the same program services.⁶¹ Only 21 States (42 percent) report that all of their State’s AAAs cover each of the

legislatively mandated services.⁶² The reasons cited for access discrepancies include differing program philosophies, eligibility criteria, funding streams, and design and administration of services.⁶³

Access to caregiver services is also hindered by shortages among professionals and paraprofessionals in rural areas. Access difficulties in rural areas are caused by both a dearth of providers but also a lack of available modes of transportation.⁶⁴ Geographic distances are also a major barrier because a frail elderly person cannot travel long distances. Finally, access to services can be limited by the caregiver’s work schedule.⁶⁵

Increased use of technology, such as telemedicine, Internet and email, has been proposed to help rural areas address their workforce shortage and health care access issues. However, the expertise and equipment necessary to implement health care technology is often unattainable in rural areas. According to a recent Pew study, rural homes are less likely (52 percent) to use the Internet than urban homes (67 percent).⁶⁶

Nevertheless, telemedicine, Internet web sites and other technologies are particularly enticing for rural areas where sparse population, great geographic distances and shortages of health care personnel make access to, and delivery of, services difficult. For the rural caregiver, the applications of such technology could, for example, help address the isolation often associated with elderly caregiving through access to online support groups and educational programs. In addition, more use of technology could also help standardize caregiver support efforts and enhance program outreach efforts. (This *2006 Report to the Secretary* contains a chapter devoted to the use of health information technology in rural health care delivery.)

Caregiver Assessment

The Committee recognizes an additional area of unmet need—that of caregiver assessment. Only one-fourth of the States currently use a uniform assessment tool for their home- and community-based programs for the elderly and adults with disabilities. Furthermore, family caregiving is a component in just five States’ uniform assessments.⁶⁷

While *State of the States in Family Caregiver*

Support does provide important information about the state of caregiver support in the nation, we can only guess at the rural implications of the findings. This is because the data were not collected and examined in a way that would identify rural and urban differences. Therefore, we can only offer proxies and consider largely rural States for drawing any conclusions. This points to an important untapped area of information. Rural data from the human service side of the Department needs to be captured. The health-related components of HHS are slowly changing their data structures to illuminate urban/rural differences. The Committee would like to encourage the Secretary to require that all survey instruments within the Department collect, evaluate and report data in a geographically specific way that identifies rural characteristics. Such standardization of efforts could be based on previous successes such as those realized in the Health Resources and Services Administration's Maternal and Child Health Bureau.

National Aging Program Information Systems (NAPIS)

The National Aging Program Information System (NAPIS) is a reporting system for services authorized under the Older Americans Act (OAA) that are delivered by the States and their sub-State area Agencies on Aging. NAPIS was first implemented in FY 1995 and continues to collect data on an annual basis. Most of the data are in the form of statewide totals; individual data are not reported. Some data on the characteristics of the sub-state area agencies on aging are also captured. The NAPIS system reports unduplicated counts of such OAA services as personal care, homemaker, chore, home delivered meals, congregate meals, transportation, legal assistance, information and assistance, and more. Detailed client profiles are reported including breakdowns by race/ethnicity and functional (ADL/IADL) status. The Administration on Aging releases detailed data tables for each year. At the present time, the data are available through 2003.

FY 2005 will be the first year that State Units on Aging (SUA) have data from Title IIIIE. The SUA will complete utilization and expenditure profiles for the NFCS programs to provide program administrators,

policymakers and others more consistent programmatic and expenditure data across the States. Despite these efforts, rural caregiving data from the National Family Caregiver Support program remains limited to age and race variables. The dearth of data specifically related to rural health and human service programs is a problem across the entire HHS system. The Committee recommends that, as a first step to remedying the rural information gap, the Secretary encourage AoA to adjust NAPIS to better reflect rural NFCS data.

Current HHS and Governmental Role

Some 225 HHS programs serve rural communities. Despite this level of support, rural advocates find that these programs are less effective than they could be. Because each program in the Department has its own assessment, application, implementation and evaluation requirements, rural communities have difficulty accessing resources that could be available to them. Coordination and standardization of program requirements is even more complex at the State and local levels.⁶⁸ The most limiting factor contributing to fragmentation and lack of coordination of health and human services in rural areas is the separation of primary health care, behavioral health care and social service funding and delivery mechanisms. Although health status and social welfare conditions are closely associated with one another, in many cases Federal, State and local planning efforts continue to address them separately.

Research reported in *The Journal of the American Geriatrics Society* reveals that caregiver well-being, rather than patient characteristics, are important predictors of whether a sick or disabled elderly individual is cared for. Because of the stress associated with caregiving, when evaluating the need for institutionalization, practitioners must take into account the caregiver support system.^{69,70} Some support for caregivers is provided through the Administration on Aging, established in the Older Americans Act of 2001, the Home and Community Based (HCBS) waivers pro-

Continued on page 55

Aging and Disability Resource Centers

The Aging and Disability Resource Center (ADRC) Grant Program, is part of the President's New Freedom Initiative, which encourages expansion of efforts at the Federal, State and local levels to provide programs and services to individuals with disabilities in community-based settings. The ADRC grant program is a cooperative effort of the Administration on Aging and the Centers for Medicare & Medicaid Services, to assist States in their efforts to adhere to the President's Initiative. The program creates a single system of information and access for all persons seeking long-term support to minimize confusion, enhance individual choice and support informed decision-making. Since 2003, 43 States have received ADRC initiative grants.

Aging and disability resource centers offer the general public a single entry point for information and assistance on issues affecting older people, people with disabilities or their families. These centers are welcoming and convenient places to get information, advice and access to a wide variety of services. As a clearinghouse of information about long-term care, they are also available to physicians, hospital discharge planners and other professionals who work with older people or people with disabilities. Services are provided through the telephone or through visits to an individual's home. Resource centers offer the following services:

Information and Assistance. Provide information to the general public about services, resources and programs in areas such as: disability and long-term care related services and living arrangements; health and behavioral health; adult protective services; employment and training for people with disabilities; home maintenance; nutrition; and family care. Resource center staff will provide help to connect people with those services and to also apply for SSI, Food Stamps and Medicaid, as needed.

Long-Term Care Options Counseling. Offer consultation and advice about the options available to meet an individual's long-term care needs. This consultation will include discussion of the factors to consider when making long-term care decisions. Resource centers will offer pre-admission consultation to all individuals with long-term care needs entering nursing facilities, community-based residential facilities, adult family homes

and residential care apartment complexes to provide objective information about the cost-effective options available to them. This service is also available to other people with long-term care needs who request it.

Benefits Counseling. Provide accurate and current information on private and government benefits and programs. This includes assisting individuals when they run into problems with Medicare, Social Security or other benefits.

Emergency Response. The resource center will assure that people are connected with someone who will respond to urgent situations that might put someone at risk, such as a sudden loss of a caregiver.

Prevention and Early Intervention. Promote effective prevention efforts to keep people healthy and independent. In collaboration with public and private health and social service partners in the community, the resource center will offer both information and intervention activities that focus on reducing the risk of disabilities. This may include a program to review medications or nutrition, home safety review to prevent falls, or appropriate fitness programs for older people or people with disabilities.

Access to the Family Care Benefit. For people who request it, resource centers will administer the Long-Term Care Functional Screen to assess the individual's level of need for services and eligibility for the Family Care benefit. Once the individual's level of need is determined, the resource center will provide advice about the options available to him or her—to enroll in Family Care or a different case management system, if available, to stay in the Medicaid fee-for-service system (if eligible), or to privately pay for services. If the individual chooses Family Care, the resource center will enroll that person in a CMO. The level of need determined by the Long-Term Care Functional Screen also triggers the monthly payment amount to the CMO for that person.

For more information, see <http://dhfs.wisconsin.gov/LTCare/ProgramOps/Pre-Admission.HTM> and <http://dhfs.wisconsin.gov/LTCare/FunctionalScreen/INDEX.HTM>.

(Continued from page 53)

gram, Family and Medical Leave Act of 1993, and the Family Caregiver Support Program.⁷¹

The Administration on Aging (AoA)

AoA was established within the Department in 1965 through the enactment of the OAA. The AoA recognizes the challenges of serving the isolated rural elderly and their families and works to identify vulnerable elderly in rural areas through its aging network. The Network consists of 56 State Units on Aging and 655 area agency on aging (AAA) programs. AAAs provide local-level program planning that supports the development of home- and community-based forms of long-term care. Rural aging programs and support services confront unique barriers that impede access to services and limit choices of service professionals and provider organizations. Often, the rural AAA becomes the direct provider and/or sponsoring partner in the development of home- and community-based systems. The AoA administers NFCSP, one of the nation's largest providers of caregiver services, which is described below.

Home and Community-Based Services (HCBS) Waiver Program

In 1981, the Medicaid Home and Community-Based Services (HCBS) waiver program was established under section 1915(c) of the Social Security Act. States may request waivers of certain Federal requirements in order to develop home- or community-based treatment alternatives. Under the waiver program, programs need not meet the statewide availability, comparability, and community income and resource rules requirements for the medically needy. The authorizing legislation allows States to request and provide homemaker/home health aide services, personal care services, adult day health, habilitation, case management, respite care and "other" services.

HCBS waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for defined groups: per-

sons with mental retardation, mental illness or physical or developmental disabilities, and the elderly. The HCBS legislation also gave States a way to serve people in their own homes and communities for the first time with services not otherwise available through their Medicaid programs. The waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.

Since passage of the original legislation, Congress has expanded the waiver authority to individuals who would otherwise require hospital-level care. All 50 States offer some form of HCBS, however there is variation in the programs offered.^{72,73} The majority (34 percent) of States administer these centrally through the State Unit on Aging.

Americans with Disabilities/New Freedom Initiative/ Olmstead Act

The President signed Executive Order 13217, the New Freedom Initiative, in 2000 to renew emphasis placed on helping individuals with disabilities to achieve the greatest independence possible by the Americans with Disabilities Act of 1990. Part of this initiative was a self-assessment of the Department that revealed the five major types of barriers to community living for people with disabilities, one of which was the recognition of a "need for greater assistance to families and informal caregivers."⁷⁴ In response, the Department developed a comprehensive policy plan to address the areas of deficiency found through the self-evaluation. The Department plan proposed assistance to families and informal caregivers through a Medicaid demonstration project and a waiver. The demonstration project would allow States to include respite as a Medicaid service. The waiver program would provide States greater flexibility to support families within cost-neutral budgets.

The 1999 Supreme Court case, *Olmstead v. L.C.*, interpreted Title II of the Americans with Disabilities Act. Through its decision, the Supreme Court challenged Federal, State and local governments to develop more community-based programs and services that would serve individuals with disabilities in the most

integrated setting possible. The Committee advocates more assertive oversight of the Olmstead act, which requires each State to take action to expand caregiver services. These services are mandated based on the recognition that a community-based system of care needs a caregiver component to be entirely effective.

Alzheimer's Disease Demonstration Grants Program

This program was established by Congress in 1992 (Section 398 of the Public Health Services Act) and is managed by AoA. The grant program helps States support effective models of care for persons with Alzheimer's disease and their caregivers. The program is designed to improve responsiveness of the home- and community-based care system to persons with dementia including underserved minority, rural and low-income persons. Mandated provisions include the following support services: respite care, home health, personal care, companion care, day care, legal rights education, and information and counseling. The Committee is confident of the successes already realized by this grant program and encourages the development of best practices models that can be replicated in underserved areas, particularly minority and rural communities, in all 50 States.

The Family and Medical Leave Act (FMLA)

In 1993 the FMLA was signed into law, officially acknowledging the role of families in providing longer-term care. FMLA entitles eligible employees to take up to 12 weeks of unpaid, job-protected leave in a 12-month period for specified family and medical reasons. The law guarantees that businesses will recognize the needs of their employees to provide eldercare and is administered by the Department of Labor's Employment Standards Administration, Wage and Hour Division, for all private, State and local government employees, and some Federal employees.

National Family Caregiver Support Program (NFCSP)

NFCSP, or Title III-E of the Older Americans Act Amendments of 2000, acknowledges that family caregivers are an important part of the long-term care system in this country. The program provides caregivers of older adults (age 60 years and older) and grandparents raising grandchildren (not more than 18 years of age) with additional funds to support activities related to caregiving. Most funds are allocated to States through a congressionally mandated formula that is based on the State's proportionate share of the 70+ population.

In FY 2001 \$125 million was appropriated for the program and the appropriation has increased in each successive year since (\$141.5 million in FY 2002; and \$155.2 million in FY 2003). The program calls for all States, working in partnership with local area agencies on aging (AAAs) and faith- and community-service providers and tribes to offer five direct services that best meet the range of caregivers' needs. The five direct services are:

- **Information** to caregivers about available services;
- **Assistance** to caregivers in gaining access to supportive services;
- **Individual counseling, organization of support groups, and caregiver training** to assist caregivers in making decisions and solving problems relating to their roles;
- **Respite care** to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- **Supplemental services**, on a limited basis, to complement the care provided by caregivers.

States are required to give priority consideration to: 1) persons in greatest social and economic need (with particular attention to low-income, minority individuals); and 2) older individuals providing care and support to persons with mental retardation and related developmental disabilities. In a nominal sense, the prior-

ity consideration given to those in great social and economic need is a nod to the rural community since the level of poverty and the degree of rurality of an area are often connected. The NFCSP was modeled after successful programs in States such as California, Pennsylvania, New Jersey and Wisconsin and has been considered a success. Advocates feel that the program is underfunded, however. The Committee supports the expansion of the Family Caregiver Support Act for many reasons, including the proven cost-effectiveness of caring for sick or disabled family members at home, as opposed to institutional facilities. The Committee encourages the establishment of three-year research grants to learn more about the rural application of the five service areas. In addition, recognizing that the major cohort of caregivers is between the ages of 40 and 70 years, the Committee favors expanding Title III program eligibility for caregiver services to individuals 50 and older (currently eligibility starts at 60 years). Finally, the Committee would also like to see more support for faith-based organizations that recognize caregivers and offer services specifically with intent of alleviating the stress of caregiving.

Program of All-inclusive Care for the Elderly (PACE)

The PACE program was designed 20 years ago as an adult day-care program for Chinese-American elderly in San Francisco. Today, 19 States have PACE as an option in their Medicaid program. PACE programs provide the entire continuum of community-based social and medical services to seniors with chronic care requirements and their families. The program is founded on the recognition that community care is better for the well-being of both the older adult and their informal caregivers. An interdisciplinary team consisting of professional and paraprofessional staff, and the caregiver, assesses participants' needs, develops care plans and delivers all services (including acute care services and nursing facility services).

To participate in the program an individual must be age 55 or older, be certified by their State as in need of nursing home care, be able to live safely in the com-

Continued on page 59

Grandparents as Caregivers of Children

While not a new phenomenon, the number of children raised by relatives has increased dramatically over the past 25 years; the vast majority of these children are raised by grandparents.^{1,2} Nationally, more than six million children are living in households headed by grandparents or other relatives. These adult caregivers—often called kinship caregivers—take on this responsibility because they want to keep their families together; they love their grandchildren, and want to keep them healthy and safe. At the same time, kinship caregivers often face unexpected lifestyle changes. The challenges they face can be physically, emotionally and financially overwhelming, compromising their capacity to provide unconditional love, build trust and serve as strong adult role models. There are many reasons why children might come under their grandparent's care. Some of the common reasons grandparents or other relatives have taken on the responsibility of surrogate parenting, when the biological parents are unwilling or unable to do so, include drug and alcohol abuse, child abuse and neglect, mental health problems, illness (including HIV/AIDS) and death, incarceration, family violence, and other family and community crises.

Most of these grandparents take on the care of their grandchildren before State departments of health and human services become involved, thereby saving the State the cost of child protection services and foster care. Nearly four-fifths of these relatives are providing “private” or “informal” kinship care.³ In rural States, relatives may make even less use of “public” or “formal” kinship care. For instance, less than 10 percent of kinship families in Maine are involved in the State foster care system. It is estimated that grandparents informally care for about 12 times as many children as the nation's foster care system and save the country more than \$6.5 billion a year.⁴

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(Grandparents, cont. from previous page)

Key challenges that grandparents and other parenting relatives face include financial security, accessing community resources and mental health concerns. Financially, 19 percent of grandparent families were living in poverty in 1999, compared to 14 percent of all families with children.⁵ In addition, nearly two-thirds of children in kinship care lived below 200 percent of the poverty line.⁶ Reasons include the extra expense of children, upgrading inadequate housing and legal costs. Therefore, caregiving grandparents need to either stretch a fixed income, or, if working, reduce work hours or pay for childcare.

Mental health services are also essential because all children in kinship care have experienced some family crisis. Many are dealing with the impact of mental health and substance abuse issues.^{7,8} Others are experiencing stress and related mental health issues as a reaction to their circumstances.^{9,10}

Organizations such as the Brookdale Foundation and Generations United, each of which promotes intergenerational programs, provide funding to programs such as the Relatives as Parents Project to support relative-headed households. Maine's Statewide Relatives as Parents Project Initiative, administered by the University of Maine Center on Aging and funded by Generations United through a grant from the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration of HHS, has issued kinship caregiver support recommendations having universal application in rural communities and regions. They include the following recommendations that: 1) families need increased financial support for on-going needs and to meet specific obligations; 2) families need assistance accessing existing services; and 3) families need quality and supportive mental health and child welfare services.¹¹

The Kinship Caregiver Support Act (S.985) was introduced in the U.S. Senate on May 10, 2005. It would establish a Kinship Navigator Program, establish a Kinship Guardianship Assistance Program, ensure written notice to relatives when children enter foster care, and allow States to have separate licens-

ing standards for kin and non-kin foster parents. This Act would help grandparents and other relatives raising children both within and outside the child welfare system.

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(Continued from page 57)

munity at the time of enrollment and live in a PACE service area. Any individual meeting these criteria can be enrolled. Although all PACE participants must be certified to need nursing home care to enroll in PACE, only about seven percent of PACE participants reside in a nursing home nationally.⁷⁵ PACE pays for nursing home services, as needed, and continues to coordinate the participant's care.

Rural PACE

Because rural counties have a higher proportion of seniors than urban counties and are also less likely to have access to adequate community-based services, rural seniors often have few options when they have long-term care needs. The PACE model allows frail elderly at high risk of institutionalization to remain in their home environment by offering integrated supportive services. The PACE model has been successful in many different communities and interest has grown in adapting the model to serve older adults in rural areas. One reason experts feel PACE could be viable in rural areas is that reimbursement under PACE is a monthly capitation rate paid by the Centers for Medicare and Medicaid Services (CMS) to the PACE provider. Capitated financing allows providers to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems. In addition, the flexibility of the program supports adaptation to the variety of rural communities and their available services.

Establishing the PACE model in rural areas means facing special challenges. By definition, rural areas lack the population density that may be required for the program to work well. Most rural areas are also significantly short of providers of all kinds, making a program that depends on the integration of many service providers untenable. On the other hand, proponents of the expansion of PACE into rural America expect retention and even recruitment of providers in rural areas to improve with PACE. They predict that rural providers will be able to maintain an adequate livelihood with PACE and will appreciate the support of the interdisciplinary team approach to caring for participants. The most significant challenge for most

rural communities will be the high start-up costs associated with PACE that are difficult to obtain in resource-strapped rural regions.

The Office of Rural Health Policy (ORHP), along with the Division of Nursing, Division of Medicine and Dentistry and the Quentin N. Burdick Program located within the Bureau of Health Professions, have been working together on a Rural PACE Technical Assistance Project. The initial goal was to determine the level of interest of PACE in rural communities and then to determine if PACE is a viable option in their areas.

A contract is in place with the National PACE Association (NPA) to provide technical assistance to rural entities interested in the PACE model. There were 200 organizations that initially contacted NPA requesting more information on the technical assistance process. After each organization completed an initial market self-assessment, NPA went on to work in depth with 21 organizations. An evaluation report is currently being completed by NPA to determine the success of the technical assistance process.

With the expenses of starting up a PACE program in a rural area in mind, the Community Options for Rural Elders (CORE) Act, S. 1067, was introduced in the Senate May 18, 2005, by Senators Blanche Lincoln (D-AR), Sam Brownback (R-KS), James Jeffords (I-VT) and Byron Dorgan (D-ND). The legislation offers assistance to health care providers working to develop PACE organizations servicing rural areas. The CORE Act would provide start-up funds of up to \$750,000 per program with total start-up funding limited to \$7.5 million across all programs. The legislation would fund approximately 10 Rural PACE programs and would offset any outlier costs so that the pilot program does not place the organization at financial risk.

The Committee acknowledges the opportunity the PACE model provides for rural caregivers and supports the Jeffords Bill and the expansion of PACE to rural areas. However the Committee also suggests that the target population for PACE participation be adjusted to include individuals in need before they become nursing home eligible. Addressing the needs of sick or disabled individuals before their condition deteriorates to the point that institutionalization is needed is both humanitarian and cost-effective.

Conclusion

The 75 million aging baby-boomers in this country will, at some point, require some form of in-home care and, for the majority, the caregiver will be a spouse, child or grandchild. Family members who assume the role of caregiver come from all socioeconomic levels, races, geographic locations and differing work status. The financial, emotional and physical stresses of caregiving, along with the isolation felt by caregivers, are exacerbated for those in rural area where services designed to assist caregivers are minimal.

Few studies recognize the specific challenges rural caregivers face. Rural caregivers are more isolated than their urban counterparts and thus would benefit from social support, financial assistance, training and information on caregiving, respite options and accessible community programs.

Recommendations

The Committee encourages the Secretary to take critical steps to assist rural caregivers through the following recommendations:

Standardization of Caregiver Programs:

- *The Secretary should encourage standardization of rural caregiver programs and uniform availability of services in rural areas across States and the nation.*

State of the States in Family Caregiver Support reveals that differences in program availability, design and benefit exist within States individually and across the nation. The Department should take the lead in efforts at standardization and uniformity of caregiver programs and services. Such an undertaking will require inter- and intrastate agreement about mission and philosophy, eligibility criteria, funding priorities, program design and administration of services.

Rural-Specific Data:

- *The Secretary should require the Administration on*

Aging, the Center for Medicare and Medicaid Services and the Health Resources and Services Administration programs to capture rural-specific data.

The Committee recommends that all survey instruments within HHS be required to collect and evaluate data in a way that identifies rural characteristics. The NAPIS database, specifically, should begin to capture data on rural caregivers. The Committee is aware that no Department-wide definition of “rural” exists. As long as this situation persists, researchers, program administrators and policymakers will be unable to truly determine and report the extent of rural need because the key Federal organizations do not evaluate programs with a uniform rural geographic standard. The health-related components of HHS are slowly changing their data structures to illuminate urban/rural differences. Such standardization of efforts could be based on previous successes such as those realized in the Health Resources and Services Administration’s Maternal and Child Health Bureau.

Funding for the National Family Caregiver Support Program (NFCSP):

- *The Secretary should authorize a study to determine adequate funding requirements for rural family caregiver services under the NFCSP.*

The Committee commends the work of the NFCSP and recognizes its success, however, the Committee realizes that the program is in great need of enhanced funding. Since it was authorized, the range and scope of NFCSP services have expanded but program funding, though increased annually, has not kept pace. Gaps in service and variation of availability of caregiver services in rural areas across States remain problematic due to inadequate funding.

Eligibility for Family Caregiver Support services:

- *The Secretary should expand eligibility for Family Caregiver Support services to include persons 50 and older.*

In recognition of the growing contingent of younger caregivers, the Department should work to lower the eligibility age from 60 to 40 and older.

Best practices in rural family caregiving:

- *The Secretary should ensure that best practices in rural family caregiving be identified, studied and publicized in a number of areas.*

The NFCS programs should specifically identify and promote rural best practices. In addition, rural best practice models for State home-based family caregiver waiver programs should also be widely distributed. The Florida legislature is considering a bill (S.B. 88 & H.B. 49) to promote best practices among informal caregivers. The legislation under consideration promotes caregiving as a non-licensed paraprofessional activity and encourages the use of caregiving best practices. The bill would also create the Florida Caregiver Institute, an independent not-for-profit corporation that would develop policy recommendations to improve the skills and availability of direct care workers. The Secretary should establish a working group to consider piloting this work in other States.

In addition, the Secretary could use the Alzheimer's Disease Demonstration Grant program, a successful model that encourages the development of best practices models, which can be replicated in underserved areas, particularly minority and rural communities, in all 50 States.

Assessment of rural caregiver needs:

- *The Secretary should encourage timely assessment of rural caregiver needs as part of the NFCS program.*

Caregiver assessment was identified in *State of the States in Family Caregiver Support* as one of the top five needed technical assistance and training areas. Screening of caregivers should be done in the primary care setting as it has been shown that early assessment of caregivers needs helps prevent institutionalization of the care receiver upon crisis.

National social marketing campaign on rural caregiving:

- *The Secretary should create a prominent, national social marketing campaign on rural caregiving.*

The Department's Administration on Aging should oversee a social marketing campaign to educate rural Americans about the difficult role of caregivers and the family caregiver support programs available to them. This campaign must use plain, easily understood language.

Persistent workforce shortage in rural areas:

- *The Secretary should continue to work to eliminate the persistent health and human services workforce shortage in rural areas.*

The need for more providers and the limited access to services in rural areas were cited as two of the top five needs listed in *State of the States in Family Caregiver Support*.

Rural application and impact of NFCSP:

- *The Secretary should establish a research grant program to study the rural application and impact of the five required NFCSP service areas.*

Lower the match requirement for the Title III E program:

- *The Secretary should lower the match requirement for the Title III E program from 25 percent to 15 percent, thus aligning it with the match required of other AoA programs.*

Encourage better coordination among centralized State Units on Aging and Area Agency on Aging services in rural States:

- *The Secretary should encourage the centralized State Unit and Area Agency on Aging to coordinate with the Area Agency on Aging in rural States.*

The Committee observed during its site visits that the use of the centralized administration of caregiver services through the State Unit on Aging to be problematic, especially in large rural States. The Committee discovered that uneven information distribution within the State caused poor collaboration among local and State service providers. Committee members saw firsthand some of the shortcomings of centralization, for example, local program directors being unaware of the other State and local services that are available to their clients.

Relationship between rural caregiver stress and health:

- *The Secretary should encourage more research on the links between caregiver stress and the consequence of poorer health among rural caregivers.*

The impact of providing long-term home care to loved ones is immensely debilitating to the caregiver. Isolation, resentment, guilt, anger financial difficulties in addition to missed work, all plague the caregiver. One out of three caregivers reports their own health to be fair or poor. Research shows that informal caregivers suffer from high levels of stress, burnout and insomnia and are more likely to use psychotropic drugs. However, this research does not identify differences between the stresses of rural caregivers as compared to their urban counterparts.

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Acronyms Used

AAA - Area Agency on Aging	MMA - Medicare Modernization Act (also known as Medicare Prescription Drug, Improvement and Modernization Act)
ADL - Activities of Daily Living	MPPC – Maine Primary Partners in Caregiving
ADRC - Aging and Disability Resource Center	NACRHHS - National Advisory Committee on Rural Health and Human Services (also known as “the Committee”)
AHIC - American Health Information Community	NAPIS - National Aging Program Information System
AHRQ - Agency for Healthcare Research and Quality	NFCSP - National Family Caregiver Support Program
AHEC - Area Health Education Center	NHIN - National Health Information Network
AoA - Administration on Aging	NLM - National Library of Medicine
ASPE - Assistant Secretary for Planning and Evaluation	NPA – National PACE Association
AWP - Average Wholesale Price	OAA - Older Americans Act
BPHC - Bureau of Primary Health Care	OAT - Office for the Advancement of Telehealth
CMS - Centers for Medicare and Medicaid Services	ONCHIT - Office of the National Coordinator for Health Information Technology
CORE - Community Options for Rural Elders	OPA - Office of Pharmacy Affairs
COWs - Computer On Wheels	ORHP - Office of Rural Health Policy
DOQ-IT - Doctors Office Quality–Information Technology	PACE - Program of All-inclusive Care for the Elderly
DSH - Disproportionate Share Hospital	PBM - Pharmacy Benefit Manager
EHR - Electronic Health Record	PCP – Primary Care Physician
FMLA - Family and Medical Leave Act of 1993	PHR - Personal Health Record
GAO - Government Accountability Office (formerly General Accounting Office)	PhRMA - Pharmaceutical Research and Manufacturers of America
HCBS - Home & Community Based Services	QIO - Quality Improvement Organization
HHS - U.S. Department of Health and Human Services	RFI - Request for Information
HIT - Health Information Technology	RFP - Request for Proposal
HRSA - Health Resources and Services Administration	RHIO - Regional Health Information Organization
IAIMS - Integrated Advanced Information Management System	RWJF - The Robert Wood Johnson Foundation
JCHC - Johnson County Health Center	SCHIP - State Children’s Health Insurance Program
IADL - Independent Activity of Daily Living	SHIP - Small Rural Hospital Improvement Program
IOM - Institute of Medicine	SUA - State Unit on Aging
IT - Information technology	
MARP - Medication Access and Review Program	