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Expanding Rural Elder Care Options: Models That Work

Proceedings from the 2008 Rural Long Term Care: Access and Options Workshop

Presented by the Rural Long Term Care Workgroup

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The Rural Long Term Care Workgroup

The 2008 Rural Long Term Care: Access and Options Workshop was organized by The Rural Long Term Care Workgroup. The Workgroup’s members share an interest in improving rural elders’ access to the full continuum of care options. Participating organizations are:

- Administration on Aging, Department of Health and Human Services (DHHS)
- American Association of Homes and Services for the Aging
- American Association of Retired Persons
- American Health Care Association /National Center for Assisted Living
- National Association of Area Agencies on Aging
- National Association of City and County Health Organizations
- National Association of Community Health Centers
- National Home Care and Hospice Association
- National Hospice and Palliative Care Association
- National PACE Association
- National Rural Health Association
- NCB Capital Impact
- Office of Rural Health Policy, Health Resources and Services Administration, DHHS

Membership in the workgroup is open to health and aging service providers, professionals and organizations that share the Rural Long Term Care Workgroup’s interests. To join the workgroup, please contact Peter Fitzgerald at peterf@npaonline.org or 703/535-1521. Additional information about the Workgroup and tools to support long term care options in rural communities can be found at the Workgroup’s website www.ruralcare.org.

The Rural Long Term Care Workgroup is grateful to its member organizations that sponsored the costs of the workshop:

- National PACE Association
- Administration on Aging, DHHS
- NCB Capital Impact
- American Health Care Association/National Center for Assisted Living
- National Home Care and Hospice Association
- American Association of Homes and Services for the Aging
- National Hospice and Palliative Care Organization

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Expanding Rural Elder Care Options: 
Summary of the Rural Long Term Care Workshop

Executive Summary

Rural communities and elders need better access to elder care options that enable them to continue to live in the community. Despite a larger proportion of the population over age 65 than urban and suburban America, rural communities lack the services and care coordination systems older adults need to continue living independently in their own communities as they age.

In November 2008, the Rural Long Term Care Workgroup convened a national Rural Long Term Care: Access and Options Workshop to identify lessons and strategies for building and sustaining rural community-based elder care services. Finding and building on successful models is an important step towards addressing the challenges faced by rural elders seeking care options in their communities. These options include home, community, and facility-based care supported by care coordination systems that enhance autonomy and quality of life of rural elders. These proceedings of the Workshop are organized around the following topics:

1. The challenges and opportunities for expanding rural elder care options;
2. Five rural elder care models that work;
3. A Rural Elder Care Options Model, a web-based, interactive tool that rural communities can use to customize the options to their specific community;
4. The organizational attributes and strong partnerships needed to build rural community options for elder care;
5. Strategies for increasing access and options for elder care in rural communities; and
6. Steps to move forward in building rural communities that support elder care.
1. The Challenges and Opportunities for Expanding Rural Elder Care Options

Rural elders often go without care rather than accept care from the limited choices available to them. In confronting this lack of care options, rural communities have both significant assets and challenges. Rural America has a disproportionately larger population of older adults needing elder care services yet faces greater difficulties developing services to address this need. Rural access to community-based care options is more limited than in urban and suburban areas reflecting, among other things, the higher costs of care in rural areas, limited state and federal resources to support expanded elder care options, and the challenges of coordinating state and federal funding to support coordinated, community-based care services. Although challenged in a number of ways, rural communities also possess important assets with which to build stronger elder care systems. Local rural community organizations can often mobilize, partner, and innovate more easily and, as demonstrated by the models featured in this Workshop, are already doing so to address the needs of their rural elders. These local initiatives may be the most important building blocks for the systems changes needed to offer greater access to community-based elder care options.

Rural Communities Have Greater Need but Less Access to Elder Care Options

A key finding of the Workshop was that rural elders are less likely than urban elders to have access to home and community based services. Studies have shown a higher use of nursing home services among the rural elderly and lower rates of home health and other community-based, in-home service use.¹ New and innovative elder care approaches will be needed to address the growing need for elder care in rural communities. Future innovations will confront reduced capacity for informal care giving² and a more limited array of community services in place.


² Out-migration of youth has resulted in a greater concentration of seniors in many rural areas, particularly in certain sections of the country such as the Plain states and the Midwest region. One result of the out-migration is decreased availability of family care givers for those residents who choose to age in place.
Isolation and Depression in Rural Elders

In the absence of expanded community-based elder care options, many rural elders will choose to remain in their homes rather than seek care in facility-based (e.g. nursing home) services. As a result, patterns such as the increased social isolation and depression of rural elders, due in part to the greater distances in rural housing patterns, will continue. This pattern is particularly harmful given the fewer behavioral and mental health resources available to assist rural elders dealing with depression and other mental illnesses.

Service Capacity and Workforce Challenges Limit Rural Elder Care Options

The challenges affecting all community-based long term care systems, including transportation, housing, and workforce, tend to be more pronounced and more difficult to address in rural communities. Transportation is an enduring challenge that is often the hardest and most expensive problem to solve for organizations trying to address the need for community-based long term care in rural areas. Poor housing stock in many rural areas poses problems for efforts to keep people in their homes and for innovative programs to use existing housing stock to support alternative housing options (e.g. assisted living). Developing and maintaining an adequate health and long term care workforce is a continuing concern in rural communities that affects the availability of elder care options for rural seniors. The out migration of young people in rural areas produces the dual problem of limiting family care giving and contributes to shortages of available workers. In turn, low wages, lack of benefits, and minimal infrastructure to support ongoing health training and career advancement opportunities means that more young people leave seeking better career opportunities. Rural physician shortages also persist. And despite the fact that family physicians represent the bulk of the rural physician workforce, rural areas lack geriatric specialists or family doctors with specialty training in the health issues of concern to an aging population.

System Financing and the Organization of the Delivery System are Challenging in Rural Areas

Too often rural elder care services are limited to post-acute care services financed by Medicare, including swing beds, skilled nursing care (SNF) and home health. Delivering Medicaid and/or state funded home care and other long term care services is more costly and complex in rural areas, limiting the availability of these services.

Housing and other supportive services are difficult to develop and sustain in many rural communities due to limited tax bases and access to private capital with which to build and operate these service programs. The inherent scale problems associated with small size and lower volumes can also make the business model for sustaining housing and other services more challenging in smaller communities.

The organization of the delivery system impedes efficient and effective care for rural elders. Specifically, the continuing lack of integration between the primary, acute, and long term care systems undermines care coordination and continuity. As in many urban areas, rural physicians, hospitals, and other post-acute and long term care providers have difficulty finding common ground to work together to meet the needs of the populations and the areas they serve. In some communities, rural hospitals have expanded their post acute care services to meet the home health and nursing home care needs of the community.
only to be forced to eliminate these services due to financial losses. Rural hospitals have also developed non-medical residential long term care options such as retirement communities and assisted living facilities. But the capacity of rural hospitals to do so is often limited to wealthier communities and may be less feasible in lower socio-economic areas.

Federal Policy Lacks Coordination and Support for Rural Capacity Building

While there are important Federal policies and programs that extend and support better elder care options in rural communities, these efforts are relatively modest in size and scope. Moreover, these efforts have been largely uncoordinated, and have not sufficiently targeted rural elder care capacity and system development. Appendix 1 describes the major federal initiatives supporting rural elder care.

State Policies Play Critical Role in Supporting Elder Care

State policy is critical to state and community elder care services. Medicaid is the primary source of funding for formal long term care services and state Medicaid policies are critical in determining what services are available in communities throughout the states. Over the past decade, states have been transforming their long term care policies and systems to provide more funding for community based health and supportive services with the goal of enabling older people (and those with disabilities) to stay independent in their communities as long as possible. State Medicaid and long term care policy is an important potential vehicle for supporting rural long term care service and systems development. Twelve state Medicaid programs now have Programs of All-Inclusive Care for the Elderly (PACE) serving rural communities. Most states, however, have not examined the status of their rural long term care systems or considered strategies for strengthening those systems. Little is known about the effects of broad-based state policies and program innovations in rural areas. For example, most states have significantly expanded federal Medicaid waiver programs to provide home and community based services yet we know little to nothing about access to these services in more rural areas. Likewise, the impact in rural areas of the significant expansion of non-medical residential care programs is largely unknown.

Rural Communities Can Lead the Way

Despite these challenging times, the Workshop’s featured programs demonstrate that there are rural elder care models that offer significant promise for building a system with more options, improved coordination, and better continuity of care across the primary, acute and long term care sectors. The communities served by these programs, and many others across the country, are mobilizing local resources to develop and enhance elder care support services and options. Churches, faith based groups, and other community organizations are stepping up to this challenge. Some rural community hospitals are filling a need by developing services or providing management and financial expertise and resources. Community colleges are partnering with elder care providers to bring training to direct care workers and collaborating with local organizations on evidence-based practices such as fall prevention and medication compliance. In a time of shrinking and limited resources, more community, regional, and state networks, collaborations and partnerships will be needed to build systems that address the growing demand for elder care options in rural communities.

3 States with rural PACE organizations are: Arkansas, Colorado, Hawaii, Iowa, Montana, New York, North Carolina, North Dakota, Pennsylvania (two organizations), South Carolina, Vermont, Virginia (two organizations)
Mobilizing community leadership and resources in support of the elder care system is a necessary but usually insufficient step toward addressing rural elder care needs. A combination of federal, state and local community leaders, partnerships, and resources is needed to support the development of expanded elder care options in rural communities around the country. Specifically, systemic changes are needed to align financing and public policies with support for the building blocks of community-based elder care in rural areas: infrastructure, local, and regional partnerships, community care providers, a health care workforce, care coordination and informed consumers. These components of rural elder care options are reflected in the experience and features of the model programs featured at the workshop.
2.

Models That Work—Care Coordination, Integration and Access

The Workshop’s featured rural elder care programs reflect a range of approaches to expanding rural community based elder care options. These five programs share several common characteristics. All serve rural populations, use an integrated care approach, and build on formal and informal partnerships to deliver services. The models include resource and referral services, care management programs, fully integrated care delivery systems, as well as home- and facility- based providers. The featured models are:

1. Lower Savannah Aging and Disability Resource Center (ADRC), Lower Savannah, South Carolina – funded by the Administration on Aging, provides information on resources available in the community to support individuals needing care and assists individuals in obtaining the services they need through direct contact with service providers.

2. Service Options Using Resources in a Community Environment (SOURCE) Program, Savannah, Georgia – uses Medicaid case management payments to provide enhanced case management services to those needing a nursing home level of care who wish to receive care in a community-based setting, selects preferred providers to deliver care to the individuals whose care is being managed by the program, and applies care paths to coordinate services across the network of preferred providers supporting an individual's care needs.

3. Piedmont Senior Health and Siouxland PACE, Programs of All-Inclusive Care for the Elderly (PACE), in Carrboro, North Carolina and Sioux City, Iowa respectively – receive combined Medicare and Medicaid capitated payments to provide all health and aging services to individuals needing a nursing home level of care who wish to receive care in a community based setting, operate a PACE Center with adult day care, primary care and therapy services, and use an interdisciplinary team to assess care needs, develop care plans, and deliver care.

4. At Home Inc., Oneonta, New York – a home care program making extensive use of telehealth to monitor and provide care to clients in rural settings.

5. Jamie's Place, Winthrop Washington – a small foster home in rural Washington State providing nursing and care coordination services in a residential setting.
These five programs share several common characteristics. All serve rural populations, use an integrated care approach and build upon formal and informal partnerships to deliver services. The models include resource and referral services, care management programs, fully integrated care delivery systems, as well as home- and facility- based providers. While these models share common features, they vary in the population served (age and acuity), the size and population density of their geographic service area, and the scope of services they offer. While some programs serve primarily or exclusively the elderly, others also serve younger disabled individuals and infants. Acuity levels vary across programs ranging from people who are certified to need a nursing home level of care, at risk of needing a nursing home, in a post-acute recovery period, or general members of the community. Service areas reflect very rural areas, small towns, and combined urban and rural areas.

Detailed descriptions of each program as well as case studies of elders being served by the programs are included in Appendix 2: Model Summaries and Case Studies.
3. A Model for Expanding and Supporting Rural Elder Care Options

The history and experience of the Workshop’s featured programs suggest several key components are needed to successfully develop and sustain rural elder care services and programs:

1. **Community infrastructure** that enables care delivery in the community, including strong partnerships to develop and sustain that infrastructure.

2. **Community-based providers supported by a rural health workforce** with the capacity to offer a full continuum of primary care, acute and post acute, and long term care services needed to enable rural older adults to be cared for in their homes and communities.

3. **Care coordination systems** that integrate care and offer options that meet individuals’ needs

4. **Informed consumers and family members** who are aware of their options and have the information they need to choose their best option

5. **Partnerships** that build and sustain community-care options
These core components are shown in Figure 1 which illustrates the system envisioned by Workshop participants. The Figure shows the individual, family, and/or friends supported by a care coordination system that integrates a range of providers and services, with a community infrastructure that enables home and community based as well as person-centered, facility based care options. To deliver care, providers draw on and are supported by the community’s infrastructure of services and resources including education, transportation, and community leadership organizations. The partnerships that build and sustain these components are reflected in the model by arrows indicating communication between the individual, family members, care coordinator, service provider, and other community organizations.

Each of the components in Figure 1 is described in further detail below.

1. Community Environment

Community infrastructure enables community-based elder care services, care coordination, and informed consumer choice. Infrastructure includes the availability of community based support services such as transportation and housing, as well as health information technologies, care coordination and other mechanisms to ensure care coordination and continuity. Each of the programs featured in the Workshop address the challenge of building community infrastructure. For example, the ADRC, SOURCE, and PACE models all include expanding transportation options as a major priority. The ADRC is working with its local government to expand transportation options by implementing the Person Centered Mobility Management model, which will serve as a “travel agent” for individuals needing transportation. The model coordinates public, private and human service transportation resources serving the region and is linked to the ADRC. The workshop’s PACE models both offer vans that transport people to the PACE center as well as to specialist care services and recreational programs.
Community-based elder care options also require housing that is available, accessible and affordable as a location in which to receive care. Jamie’s Place provides both housing and services in a small group home setting to support access to continuing care in the community.

2. Community Based Providers Supported by a Rural Health Workforce

For rural elders to have long term care options that meet their needs, both community and facility-based care providers that offer a person-centered approach are needed. Specifically, rural communities need a variety of community based home care (both skilled and personal care assistance), primary care (with a focus on care of the elderly and chronic care), mental health, and dental health providers plus a strong telehealth capacity that can deliver many of these services in or close to home.

The Workshop’s models noted the importance of investing in workforce development such as vocational high school programs, community college curriculums, career ladders and long term stability in wages and benefits. At Home Inc., the home care model serving rural communities in New York, partners with Bassett Healthcare to offer a nurse mobility program supporting licensed practical nurses seeking to become registered nurses and to obtain their Bachelor of Science in Nursing. They are also considering how to apply this mobility model to the development of radiology technicians. Jamie’s Place works with local high schools to provide volunteer opportunities that offer students insight into aging and elder care issues.

The Workshop featured three programs that provide examples of how rural elder care options can be supported. The At Home Inc program uses extensive telehealth applications to enhance its home care services for elders in rural areas. Jamie’s place applies the Greenhouse principles to the design and operation of a small foster home that offers rural elders a person-centered approach to facility-based care. The two PACE programs, Piedmont SeniorCare and Siouxland PACE, provide a full range of care services to rural elders including home care, adult day care, primary care and rehabilitation on a routine basis. Additionally, the community health center that sponsors Piedmont SeniorCare provides primary care to its rural service area and the hospice program that sponsors Siouxland PACE provides both palliative and end of life care to its community.

3. Care Coordination Systems to Integrate Care and Offer Options

Providing rural elders with options they need requires a strong care coordination role. This role addresses the need to inform individuals and families of their options, understand care needs, facilitate access to care, and integrate care delivery. Care coordination services typically provide information to individuals based on an understanding of the elder’s needs and wishes. Informing individuals includes providing educational resources to support the elder’s self-care and decision-making and providing referrals to available services. Assistance to the individual can extend to include advocating within the care system and community for the individual to ensure that their needs are met. Building on care coordination, care integration applies an interdisciplinary approach to care needs assessment and care planning, using care paths to coordinate action, and examining outcomes for effectiveness and improvement. To be effective, the care coordination role must also be longitudinal, over the course of the rural elder’s aging process and evolving care needs.

Coordinating care and services is at the heart of three of the workshops models: ADRCs, SOURCE and PACE. These three models represent an increasing level of coordination and integration, reflecting the increasing level of control the models have with regard to the resources required for care. The ADRC coordinates care by offering referral services and following up with the providers to ensure care is delivered. As a result of this follow up, the ADRC can work with the person receiving care and the range of care providers to improve care. The SOURCE model develops a care path for the enrollees it serves
and provides referrals to preferred providers in the community in order to implement the care path. SOURCE programs choose preferred providers, and require that these providers agree to the care path and to monitoring outcomes associated with the care path. Using its leverage of selecting preferred providers and making referrals, SOURCE is able to integrate care and monitor effectiveness. For the two PACE models, an interdisciplinary team of the health professionals providing care to the elder is used to assess care needs, develop a care plan, integrate care delivery and monitor outcomes. The health professionals providing care to the elder are either PACE employees or contractors of the PACE organization.

4. Informed Individuals and Families

Rural elders who are aware of their care options and understand how these options will support their quality of life are central to transforming the rural elder care system. Similarly, their family and friends must know of the care options available to them and be able to support rural elders in their choice of services. Providers offering services to rural elders need to reflect the elder’s wishes and to consult with the family members and friends who often play a critical role caring for the elder. Communities can also support elders in their independent assessment and selection of care options by assuring that elders have access to the information they need. The ADRC model in particular is focused on providing information to elders at all levels of care needs and enabling them to assemble a range of services that enhance their care options.

5. Partnerships that Build and Sustain Community Care Options

Partnerships within and among communities and providers are essential to building community infrastructure. Within rural communities where resources may be more scarce it is essential to build on existing community resources, providers and relationships. Partnerships with consumers and providers ensure that appropriate services are being developed and offered. These partnerships also promote understanding of the services by consumers and their family members. Partnerships of providers facilitate care coordination and maximize the efficient use of limited resources. Partnerships with community organizations and leaders help to develop the infrastructure and resources that expanded community-based elder care options require in rural areas.

In some cases, partnerships spanning multiple communities may be needed to gain access to services and resources that may not be available in every community. In addition to enabling communities to secure access to services and resources, such partnerships can also serve to enhance care coordination, especially when more specialized health care services only available regionally may be involved. For each component in the Rural Elder Care Options model, the partnerships within the component and across the components are essential to the successful development of community-based options.

A Tool for Community Assessment

One of the products of the Workshop has been the development of a web-based version of the model described here with interactive tools that allow for customization to describe a specific community. This product is available at www.ruralcare.org. Communities can use the model to describe current care coordination systems, service providers, community infrastructure resources and partnerships. The customized model can help to identify opportunities for increasing the care options available to their elders.
Moving Forward to Expand Rural Elders’ Care Options

Workshop participants recommended steps that rural communities can pursue to develop the core components, as represented in the Rural Elder Care Options Model, needed to expand rural elder care options. The Workshop also examined the broader system changes in financing, state and federal policies, and health information technologies needed to support expanded options.

Rural Community Building Strategies

The Workshop participants identified 7 core strategies that rural communities can pursue to expand elder care options:

- Form partnerships to design and implement change,
- Assess community needs,
- Develop and refine alternatives for expanding care options
- Build organizational capacity,
- Inform and support consumers and their family members,
- Strengthen local services and infrastructure, and
- Monitor and assess the performance of the local elder care system.

Each of these steps is described below.

Create Effective Partnerships: As previously stated, community and regional partnerships are an essential strategy for creating better long term care options in rural areas strengthen the advocacy efforts of individual organizations and enhance resource and care coordination. While the importance of developing highly functioning, integrated network partners is generally embraced, little is known about building functional, effective partnerships especially in rural communities. Development of partnerships is also hindered by the significant time, energy and resources required to establish and maintain them. However, the benefits of partnering merit the investment:
1. By combining financial resources, partners can undertake investments that would not be possible for a single organization.

2. Partners can bring value beyond direct financial support, including:
   - social capital (e.g. trust of local community members, contacts),
   - political capital (e.g. access to regulatory agencies, local policy makers),
   - intellectual capital (e.g. education, research, training expertise).
   - historical perspective and knowledge of local population, and
   - personal leadership

3. Partners are important resources to build a base for current and future leaders to address health and care needs in the community.

The programs recommended including a diverse range of partners: business leaders, consumers, health and aging service providers, community service providers (transportation, academic institutions), financial institutions, and technology experts, among others. The partnership should work to maintain awareness of new health care technologies and new models of care, such as PACE, that create new opportunities for the partners.

For many rural initiatives, the ability to partner with nearby regional centers of care, typically located in urban areas, can strengthen their ability to effect change. Consider forming a partnership or building on existing organizations that work with urban systems. This can provide access to resources (capital, services, human resources) needed to offer community-based care options in the rural area.

Assess Community Needs: Working within their partnerships, rural communities should seek to inform the expansion of community care options with an assessment of elders’ needs and the community’s current strengths, weaknesses, and capacity. Public and community input into the needs assessment will help to align any proposed changes or initiatives with the priorities of the intended service population. This input will also provide valuable information for formulating a range of ideas and approaches to expanding elder care options. Community needs assessments typically include demographics, community resources such as housing, transportation and financial resources and their ability to meet basic needs, current programs and services, and available skills and areas of expertise. Skills and expertise that are needed in the development of rural elder care options include: information and data gathering, training, financing, housing, education, public policy and technology. A number of community needs assessment tools are available to rural communities:

- The Aging Texas Well Community Assessment Tool – a nontraditional “needs assessment” tool for evaluating the capacity and potential of a community’s infrastructure for supporting individuals as they grow older. The tool includes questions covering the following areas: Community profile, Caregiving, Community Support, Education, Employment, Financial, Housing, Legal, Physical health, Protection, Recreation, Transportation, and Volunteerism. http://www.agingtexaswell.org/communityassessment/step4.html
- The Process of Community as Partner. http://connectiondev.lww.com/Products/vollman/documents/Ch08.pdf
- Self-Assessment for PACE, http://www.npaonline.org, select “Rural PACE” icon
Develop and Refine Alternatives for Expanding Care Options: In planning for changes that will increase rural elders care options, the community should encourage a range of solutions developed with input from all of the parties involved in the partnership representing aging, health and community services. In addition to the input of local individuals and organizations, communities can look to other rural communities for programs that have been effective in offering rural elders greater access to more care options. These examples of innovations from other rural communities can provide useful ideas. However, each community initiative will need to be mindful of the diversity of rural communities with respect to culture, race and class and craft a strategy and system that matches their characteristics and circumstances. Resources that provide information on rural innovations in aging include:

- Rural Assistance Center. www.raonline.org
- National Association of Area Agencies on Aging, Livable Communities.
- www.n4a.org/programs/livable-communities/

Develop Organizational Capacity: The success of any proposed initiative to expand care options will rely to a considerable extent on the organizational capacity available to implement the change. The experience of the Workshop’s featured programs demonstrates the need for strong organizational leadership, combined with effective partnerships, in creating and sustaining elder care options. Organizations leading the development of rural elder care options confront a range of financing, human resource, infrastructure and policy challenges. To address them, rural elder care organizations must cultivate and draw on the combined staff and board member leadership resources in the community partnership to become the catalysts for changes needed to build a stronger system of elder care services.

To effectively guide its efforts, each organization’s mission and vision should be understood and embraced not only by its own staff but also by the community. These mission and vision statements require a strategic plan for implementation. The plan should be revisited and updated on a regular basis to respond to changes that occur in the community and to take advantage of opportunities that arise. The organization should put in place a process for staying focused on sustainability that assures the participation of caregivers, providers and consumers in directing the growth of the organization. Organizations must also recognize their critical role in advocating for public policies that support innovation in providing elder care options for rural consumers.

Engage and Inform Consumers and Family Members: Rural communities can increase access to elder care options by informing older adults and family members of the services and resources available in the community. Supporting caregivers is an important component of this strategy.

Rural elder care initiatives will need to acknowledge that caregivers and consumers want to determine how services are delivered and where, with an emphasis on quality of life. Information alone is not sufficient as elders often need assistance contacting and working with different service providers. It is helpful to streamline access to the full range of services by making it easier with one call, one click, or one single point of entry to obtain needed services and information. Consumers need decision-making support as they consider their options. The ADRC program represented at the workshop provides information, referral and follow-up with providers on behalf of the individual and family members. Rural communities may be able to further support consumer decision making with information about preferred providers based on performance and successful integration of care. The SOURCE program featured at the workshop uses preferred providers to ensure that services are of high quality and that the service provider participates in the care coordination process.
Building stronger caregiver support services and programs is an important way to engage consumers and families. Support groups and counseling help strengthen family care giving by relieving anxiety, improving their well-being, allow them to share information about resources and coping strategies, and reducing feelings of isolation. Rural communities can develop a family caregiver support system, building on the National Family Caregiver Support Program, which is federally funded through the Administration on Aging. The program provides basic services to caregivers, including: individual counseling, support groups and education and training to help with decision and problem solving related to care giving, respite care, and supplemental services to complement existing care provided. Information about the program is available at http://www.agingcarefl.org/caregiver/NationalSupport.

Strengthen Service Providers’ Ability to Deliver Care in the Community: Rural communities may need health and aging service providers with new skill sets to support expanded elder care options. Existing providers can develop care coordination systems, increased home and community based services, staff with expertise in community-based care, and the ability to use telehealth technologies to provide care in homes across long distances. Service providers need care professionals who can work in community settings, care systems that coordinate care across the full range health and aging service providers, and health technologies that support remote care delivery.

Establish a Care Coordination System: Rural initiatives to expand elder care options will need to develop care coordination systems and resources. Development of a coordination system should involve care coordinators in the community, such as hospital discharge planners, who support transitions from one setting of care to another. The coordinators can contribute to the development of comprehensive care plans and help to achieve the support for the care plans of the individual and his or her family. The rural community should establish a process that supports a shared understanding of care needs and care plans across providers of care that:

- uses a shared assessment instrument across settings of care,
- applies outcome measures across the full range of care,
- uses evidence based clinical practice guidelines to implement shared pathways with different caregivers,
- includes incentives to link autonomous providers, and
- integrates Medicaid and non-Medicaid funded providers.

Monitor and Assess the Performance of the Local Elder Care System: Rural communities and elder care partnerships should make the elder care system accountable for the resources used, the access to services provided, and quality of care. To do this, rural communities will need transparent reporting systems to track where funds are spent and related performance, based on clear measures.

System Changes Needed to Support Rural Communities

While community efforts can make great strides in improving rural elders’ access to more care options, the success of these efforts will be affected by broader, systemic factors at the state and federal level. Specifically, payment systems, long term care policy approaches, workforce policies and programs, and the development of health information technologies will have a significant impact on local efforts.

Payment Systems: Workshop participants developed a range of ideas for modifying current payment systems to better support rural elder care options:

- Recognize the value of care integration in payments to providers by including reimbursement for primary care's role in supporting care management and eliminating “silo” funding for different segments of the health care system. Though capitation payments may be able to help in addressing
silo funding, it is important to note that in rural areas in particular managed care has often failed to deliver on this promise.

- Consider the development of a blended payment system that includes both public and private payers.
- Offer financial incentives for comprehensive community care. These incentives should address provider, consumers and infrastructure services such as housing, education and transportation.
- Recognize family and caregivers’ needs as well as the elder’s needs and incorporate their input in funding decisions.
- Provide communities with flexibility in financing so local organizations can tailor funding and programs to address unique local needs and circumstances.
- Develop more comprehensive financing of rural elder care that supports all in need across age categories, income, public and private providers, and many community partners.

**Policy Change and Innovation:** State and federal policies should be coordinated to support the development of integrated care delivery models, such as PACE, care coordination models, such as Aging and Disability Resource Centers and SOURCE, and providers that expand the care options available to rural elders, such as small foster homes, and home care with enhanced telehealth services. Medicaid programs should review payment policies to assure these policies support the development of community-based long term care options that can effectively serve rural elders. Priority should be placed on directing flexible funding to the community-based care providers and care coordinators that will expand rural elders’ options. The infrastructure available in rural communities to support elder care options, including transportation, housing, workforce education and training services, and health information technology, should be assessed to identify and address gaps. As a first step, an assessment of rural communities’ readiness to offer expanded long term care options to their elders should be undertaken. The readiness assessment should identify unmet needs, existing opportunities, and new requirements for rural elder care options.

**Workforce:** Rural areas face particular challenges in finding the workforce to make community care options available to elders. The Workshop’s discussion suggested a number of workforce initiatives to address this challenge:

- Re-evaluate scope of practice laws so that one provider can perform multiple tasks (e.g. nursing and therapy) and multiple providers can provide the same service (e.g. give medications).
- Develop career ladders for lower-skilled work force members with increased input into care planning, and reasonable wages and benefits.
- Develop vocational high school programs for health workers.
- Develop degree program for health workers at community colleges.
- Develop training programs at high school and community college levels for health information technology.

**Health Information Technologies:** Health information technologies are needed in rural areas to support expanded elder care options. The use of electronic technology is growing including expanded use of the internet, web-based information and services, and electronic monitoring of medications, sleeping patterns, and security. The Workgroup identified a range of health information technologies that should be expanded to enhance rural elders’ care options:

- Consumer and family access to the internet and websites that support access to information for assessing care options,
• Diffusion of remote health monitoring devices connected to rural care coordination and delivery organizations,
• Electronic medical health records and care path systems that are linked to support coordination of care across a range of providers and organizations,
• Internet and telephone communications to address social isolation, and
• Telehealth systems to provide access to specialist care outside the rural community.
Appendix 1

Federal Initiatives Related to Rural Elder Care

The Federal Administration on Aging (AoA): AoA has been working to extend and expand the dissemination of information about evidence-based prevention and health promotion programs and practices, recognizing the critical role that up-to-date, easy-to-use information plays for caregivers, families and individuals as they try to access long term care. This initiative has demonstrated success in reaching rural populations in many different states. However there has been no systematic assessment of the barriers and facilitators to adoption of these practices and programs in rural areas.

In addition, AoA and CMS have collaborated to establish Aging and Disability Resource Centers (ADRCs) to promote the integration of long term care information and referral services, benefits and options counseling services, and access to publicly and privately financed services and benefits, for those individuals in need of long-term supports and their families. AoA’s goal is to have an ADRC in every community that can serve as a highly visible and trusted place where people of all incomes and ages can turn for information on the full range of long term support options and a single point of entry for access to public long term support programs and benefits.

Finally, AoA has been supporting a nursing home diversion initiative targeted to those at high risk of nursing home placement and spend down to Medicaid through single point of entry/ADRC programs. The initiative promotes the use of more flexible service models, including consumer directed models. Several states are rolling the initiative out in rural areas where there is a shortage of service providers. In conjunction with this initiative, AoA is partnering with the Veteran’s Health Administration (VHA) in ten states on the Veterans Directed Home and Community-Based Services initiative where the VHA will purchase consumer directed care for qualified veterans through Aging Network providers.

Federal Office of Rural Health Policy (ORHP): ORHP manages several important programs that target rural health systems development. A major goal of the Office’s grant programs is to support hospitals, primary care providers, and others to develop sustainable rural health services and delivery systems that improve healthcare access and quality in rural communities.

ORHP’s Outreach and Network Grant Programs encourage the development of new and innovative health care delivery systems in rural communities that lack essential health care services. The purpose of the Outreach program is “to promote rural health care services outreach by expanding the delivery of health care services to include new and enhanced services in rural areas.” The Outreach program supports projects that demonstrate creative or effective models of outreach and service delivery in rural communities. The emphasis is on service delivery through collaboration and creative strategies requiring the formation of both within community network and across community networks with at least two additional partners. The community being served must be involved in the development and ongoing operations of the program, to appropriately address the needs of the population. Programs vary greatly and have brought care that would not otherwise have been available to at least two million rural citizens across the country. Through consortia of schools, churches, emergency medical service providers, local universities, private practitioners and the like, rural communities have managed to create hospice care, bring health check-ups and dental care to children and provide prenatal care to women in remote areas, among other service innovations and expansions.
The purpose of the Network Development Grant Program is to further ongoing collaborative relationships among health care organizations by funding rural health networks that focus on integrating clinical, information, administrative, and financial systems across members. The goal is to strengthen rural health care systems at the community, regional and State levels by funding these formal, horizontally or vertically integrated networks.

ORHP also administers the Rural Hospital Flexibility (Flex) Program. Created by Congress in 1997, the Flex Program allows small hospitals to be licensed as Critical Access Hospitals (CAHs) and offers grants to States to help implement initiatives to strengthen the rural health care infrastructure. To participate in the Flex Grant Program, states are required to develop a rural health care plan that provides for the creation of one or more rural health networks; promotes regionalization of rural health services in the state; and improves the quality of and access to hospital and other health services for rural residents of the state. To date, over 1,200 hospitals have converted to Critical Access Hospital status. In addition to providing support and technical assistance to CAHs, the Flex Grant Program supports hospitals and other providers and communities to develop networks of care, improve and integrate emergency medical services, and improve the quality of care in rural communities.

None of ORHP’s grant programs explicitly targets rural long term care development. Nevertheless, projects funded by these programs involve long term care providers and patients and there is considerable opportunity for rural providers and communities to flexibly use the program to support rural long term care service and systems development.

The Center for Medicare and Medicaid Services (CMS): Although rural long term care has not been a major focus of CMS policy and programs, the agency has two initiatives with important application in rural communities. With expanded authorization from the Congress in the Deficit Reduction Act of 2005, CMS has been instrumental in the expansion of PACE (Programs of All-Inclusive Care for the Elderly) programs to rural areas. PACE is a capitated benefit authorized by the Balanced Budget Act of 1997 (BBA) that features a comprehensive service delivery system and integrated Medicare and Medicaid financing. PACE programs offer a full range of needed community-based medical and supportive services for individuals over the age of 55 who are chronically ill and certified to need nursing home care. The program seeks to provide the entire continuum of care and services with the goal of maintaining their independence in their homes for as long as possible.

Currently rural PACE programs are operational in 12 states with 14 organizations supported by CMS start up grants and outlier protection for the first two years of operation. The experience to date suggests that entirely-rural PACE programs and those that are connected to urban organizations have differing advantages. Entirely-rural programs have seen advantages in terms of demand for their services due to both an absence of alternatives and the PACE organization’s trusted relationship with the community it serves. The greater relative demand in entirely rural service areas has yielded a higher enrollment per capita in these areas than in some of the combined rural and urban PACE programs. Rural PACE programs connected to urban organizations have seen advantages in terms of access to capital and human resources for development, ability to enroll from a denser service area population, and financial reserves.

Although it is not a rural initiative, the Medicare Advantage program and, in particular, Special Needs Plans (SNPs) authorized under the program, may provide an additional vehicle for developing coordinated primary, acute and long term care services in rural communities. SNPs were first authorized in December, 2003, in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA), the same legislation that created the Medicare Part D prescription drug program. A SNP is a type of Medicare Advantage plan that may restrict enrollment to specified groups of Medicare beneficiaries believed to benefit from specialty care tailored to their chronic care needs. The potential
for SNPs to become mainstream vehicles for integrating Medicare and Medicaid services to promote continuity of care for so-called dually eligible individuals became apparent soon after passage of the MMA. Although the experience with SNPs has been decidedly mixed, several states with prior managed long term care experience, including Minnesota, Wisconsin and Massachusetts, are expanding to rural areas using SNPs as the vehicle for managing care. The traditional approach has been for established urban/metro programs to expand and extend services to rural communities while one state, New Mexico, hopes to implement a program that will go statewide from the beginning. Little is known about the level of rural enrollment or the potential impact of these new managed care long term efforts in rural communities.
Appendix 2

Model Summaries and Case Studies

Each of the models featured at the workshop is described below in terms of the model's goal, location, service population, scope of services, and partners. To illustrate the impact of each model on the individuals in its community, a case study for a real person receiving care from the model, or representing a composite of real people receiving care from the model, is also provided. The five featured programs are:

1. Aging and Disability Resource Center, Lower Savannah, South Carolina

2. SOURCE, Savannah, Georgia

3. Program of All-Inclusive Care for the Elderly, Carrboro, North Carolina and Sioux City, Iowa

4. At Home Inc., Oneonta, New York

5. Jamie’s Place, Winthrop, Washington
Aging and Disability Resource Center, Lower Savannah, South Carolina

Goal of the Program: The goal of the Lower Savannah Aging and Disability Resource Center is to promote independent living in the community, streamline access to long term care for older adults and people with disabilities, serve as a comprehensive source of information that helps people make informed decisions and promote the leveraging of existing resources in the community.

Location: The Lower Savannah Resource Center is located in lower Savannah, South Carolina, a rural area of 4,000 square miles. Five of the six counties in the area are designated “health professional shortage” areas and contains two of the state’s poorest and smallest counties.

Population Served: The program serves adults of all ages, without regard to income or insurance coverage. The area served has a population of 308,000, 19% of who are over age 65 and 24% of the region’s residents have a disability.

Services Provided: The Resource Center provides information, referral and assistance including legal services, benefits counseling and a long term care ombudsman. Assistance is provided for emergency rental/housing, mobility and transportation, caregiver support, coordination with hospital discharge planners and support for issues about medications.

While the Resource Center serves adults of all ages and incomes, they have also established a program to target assistance to individuals on the Medicaid Home and Community Based Waiver waiting list. They are working with the state to revise the criteria for wait list priority to receive community based waiver services at home to shift from a first come-first serve criteria to criteria based on severity of need.

Partners: The Lower Savannah Resource Center has extensive partners including medical centers, local councils on aging, vocational rehabilitation agencies, local physicians and hospitals, providers of transportation and an independent living center, homecare providers and the program of All Inclusive Care for the Elderly. Federal funding support is provided by Administration on Aging, US Department of Transportation, Center for Medicare and Medicaid, Federal Transit Administration.
ADRC Case Study

Walter and Irene Brooks came to a presentation that the ADRC did about Medicare Part D when the benefit first came into effect. He was 79 and she was 75. The ADRC staff followed up with an appointment with the Brooks and helped them to select the best benefit plans for each of them to meet their individual needs. Mrs. Brooks called the ADRC staff about a year later to ask for help with a different issue; Walter had recently suffered a stroke and Irene was overwhelmed trying to take care of him in their home. She was distressed, and thinking of looking for a nursing home.

Mrs. Brooks was able to drive, but was having some problems with her eyesight and arthritis in her neck. She enjoyed cooking, but sometimes ran short of grocery money. She had begun to feel depressed and exhausted. The staff met with Mrs. B. and discussed alternatives in the community. The Books who were living on a limited income were aware that there were other options than providing Mr. B.’s care all on her own or turning to a nursing home. The ADRC staff helped Mrs. Brooks to learn about and explore several appropriate community-based options.

Mrs. Brooks felt that getting a periodic break would help her greatly and the Family Caregiver Support program was able to provide her with occasional sitters so that she could have some time to go to church, to tend to personal business and to take a break from the stresses of caring for Walter. Mrs. Brooks was able to use the person of her choice to stay with her husband Mr. Brooks, allowing her to get the help when she most needed and wanted it. The program then compensated her for payment of the sitters.

The ADRC staff helped to link Mrs. Brooks with a local caregiver support group, and to help her explore services offered by the local Council on Aging. Through the Older Americans Act Home Living Support program, she began receiving periodic help with some of the household maintenance chores that were most difficult for her to do. Through this same program, she was linked with a volunteer group, who removed a dead tree limb precariously hanging over her porch and driveway and who began to help maintain her yard once a month.

The ADRC’s legal services program helped The Brooks with advance directives and referred them to and paid for the services of a local attorney who helped them to set up a power of attorney. Referral to a program called Angel Food Ministries, helped Mrs. B. to turn $25.00 in grocery shopping money into $40.00 worth of groceries, stretching her resources further.

As Mr. B. had begun to take more medications, his Medicare Part D plan needed reassessing. The ADRC staff helped the Brooks to select and enroll in a different plan for him. The staff also worked with the Brooks to complete an online application for assistance from the South Carolina GAPS program, which provided 95% of the “donut hole” medication costs in their coordinating Medicare Part D plans.

Getting Mr. B. in and out of the house had become a problem for Mrs. B., since he needed a wheel chair for going out. The pathway to their driveway was uneven paver stones at
the bottom of several steps. The ADRC staff linked the B’s to a faith based group who built them a ramp with materials donated by a local lumber company. To get to doctor’s appointments with a specialist in another county, the ADRC’s mobility manager helped the Brooks to find FTA Section 5310 transportation, as Mrs. B. was uncomfortable about being able to drive safely in a strange, congested area.

Things went along pretty well for the Brooks for another year. The ADRC staff kept in contact with the Brooks, and kept them on the mailing list for the Caregiver Newsletter, a monthly publication with helpful tips on care-giving, a little humor and a section on local resources, educational programs and benefits. Mrs. B. said that getting the newsletter reminded her that we were there for them when they needed us.

Later, Mrs. Brooks needed extra help when she slipped and fell in the kitchen and sustained a fractured ankle that required her to be in a cast. ADRC staff and partner agencies in the community worked together with her daughter, who came from Chicago for a two-week stay with her parents, to set up a plan for the last three weeks of her mother’s recuperation.

The ADRC mobility manager and the local transit provider worked out the transportation that Mrs. B. wanted to get to the doctor and to physical therapy under the FTA Section 5310 contract for service. The local Council on Aging provided short-term home delivered meals for three weeks for the Brooks, and temporarily increased home-living support visits to once a week. A niece from Atlanta came on two weekends to help with shopping, cooking, and other necessary care and chores.

Mrs. Brook’s ankle healed and she was able to resume driving, cooking and caring for Mr. B. The ADRC staff told her daughter about frozen meals that the Brooks could select and order by mail to be delivered to their door and the daughter and niece “treated” the Brooks to two weeks of frozen meals. The ADRC staff recommended that Mrs. B enroll in the “Matter of Balance” program being offered at the local Council on Aging senior center through wellness program funds. Mrs. B. reported that she enjoyed the fellowship and learned some new strategies to help her avoid another fall.
**SOURCE, Savannah, Georgia**

**Goal of the Program:** The goal of SOURCE is to maintain individuals in the community and, where possible, in their homes to prevent premature placement in an institutional setting; prevent the decline in health status associated with chronic illness.

**Location:** The SOURCE model serves all the counties in Georgia, approximately half of the individuals served are living in rural communities.

**Population Served:** The program services over 14,000 people who meet state nursing home level of care criteria, who are SS eligible for Medicaid. The population currently being served is slightly younger than the general nursing home eligible population and two thirds dually eligible.

**Services Provided:** The SOURCE provides enhanced case management: communicates performance standards to preferred providers, serves as liaison to primary care providers, works with family and caregivers to assure that they are providing planned support, serves as an advocate/navigator for the patient, develops a Care Path that specifies the goals for the clients and work with preferred providers to meet Care Path goals. The Care Path establishes a standardized set of expected outcomes designed around indicators associated with chronic illness and functional impairment. The Care PACE also specifies levels based on intensifying care needs.

The SOURCE pays primary care providers a monthly fee to participate in the case management for each client cared for by the provider, who is enrolled with SOURCE.

**Coordinated Services:** The SOURCE coordinates services on behalf of the client with preferred medical and hospital care providers, preferred home care, adult day, personal care providers, preferred assisted living and nursing facility providers and transportation, EMS, Meals on Wheels and other services on an as needed basis, for each client.

**Partners:** SOURCE programs are operated by various groups such as: community hospitals, nursing facilities, Area Agencies on Aging, ARCs and private case management groups.

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**SOURCE Case Study**

Mrs. Jones is 70 years of age, has a monthly income of $635.00 and currently resides at home. She has been unsteady on her feet, suffers from COPD, hypertension and has frequent hospitalizations. She currently has an in home caregiver and was referred to the SOURCE program by her primary care provider. Mrs. Jones was admitted to the SOURCE program and went through the assessment process in order to determine individual service needs and build a personal profile by gathering medical, functional, and psychosocial information that serves as a basis for case management interaction, determine the level of care and Carepath development. She received an MDS-HC (Minimum Data Set for Home Care) assessment to determine the nursing home level of care. It was determined that Mrs. Jones had functional or cognitive impairment at a Carepath Level two. She was provided community service and personal support services 3 times per week for a total of 24 hours per week. She will be reassessed on an annual basis until her condition improves or declines.
Program of All-Inclusive Care for the Elderly (PACE)
Carrboro, North Carolina and Sioux City, Iowa

Two PACE programs were represented at the Workshop: Piedmont SeniorCare and Siouxland PACE. Piedmont SeniorCare is a PACE program developed and operated as part of a Community Health Center while Siouxland PACE was developed and is operated as part of a hospice program. The two programs are summarized below.

Goal of the Program: For Piedmont SeniorCare, the goal of the program is to keep rural elders in their communities by bringing health care to them and to bring a focus to elder care within the Community Health Center. By support families and their elders, Piedmont SeniorCare can further its mission to strengthen the community at large.

Reflecting its sponsor’s hospice mission, an important goal for Siouxland PACE is to provide a continuum of care that relieve suffering and improves quality of life for individuals and caregivers dealing with advanced illness through the end of life. Other goals include addressing the social isolation of elders, increasing the flexibility of care options (e.g. therapy to maintain functioning, not just to restore it) and serving people with complex long term care needs who may not be eligible for the Medicare hospice program.

Location: Piedmont SeniorCare is located in Caswell and Alamance counties in North Carolina. The region includes both rural and urban areas. A significant percentage of the population served (25%) is in rural Caswell County.

Siouxland PACE is located in Lemars, Plymouth County, Iowa, a rural county with a population of 22,000 that is adjacent to Woodbury County and the much larger Sioux City, Iowa. Lemars has a hospital, medical clinic, three nursing facilities, a home health agency that is affiliated with the hospital, and two assisted living facilities. Hospice of Siouxland has a satellite office at the hospital.

Population Served: Both Piedmont SeniorCare and Siouxland PACE serve a population that is defined in the PACE regulations. The PACE regulations specify that PACE programs can serve those 55 years of age or older who reside in PACE program's defined service area, are nursing home eligible, and are able to live safely in the community at the time of enrollment with the provision of PACE services.

Services Provided: Both Piedmont SeniorCare and Siouxland PACE comply with federal requirements that the PACE program provide all required health, aging and social services needed by an enrolled individual. These services must include, but are not limited to, adult day health care, recreational therapy, meals, social services, nutritional support, pharmaceuticals, primary health care, dental care, nursing, personal care assistance, skilled home health care, specialty care, acute care, nursing facility care, assisted living, transportation, and meals. The care provided to a PACE enrollee by the PACE program reflects the care plan requirements of the individual and is not limited by fee-for-service restrictions.

Partners: For Piedmont SeniorCare, the community health center worked with the federal and state agencies, community organizations and local providers. The agencies that worked with Piedmont were: the Center for Medicare and Medicaid Services, the State Division of Medical Assistance, the Area Agency on Aging, and the Department of Social Services. At the local level, Piedmont worked with community providers and health care organizations, specialty providers, hospitals, home care agencies, transportation providers, hospital discharge planners and social workers. Piedmont also formed a senior care advisory board and consulted with its Board of Directors. Financial partners include Medicare, Medicaid, Wachovia and foundations.

Partners working with Siouxland PACE included local physicians, nursing facilities, assisted living facilities, community organizations and associations, volunteers and consumers.
Case Study from Piedmont

Ralph Miller is an 87 year old male with multiple medical concerns that include: Parkinson’s disease with gait disturbance, speech and swallowing problems with drooling, visual hallucinations, sleep disturbance, cognitive and memory issues, severe chronic weepy venous stasis in legs, brawny pitting edema, recurrent stasis ulcers, chronic renal insufficiency, urinary incontinence and visual loss with macular degeneration. He was taking six different medications and supplemental vitamin b and c and ocuvite for vision.

The goals for Ralph were to help him walk better, reduce frequent urination, stop the sores on his legs and assist in ways for him to continue to be active on the farm. His wife and children indicated that he was wearing his wife out and she needed a break. They were worried about him falling and wanted him to see a urology specialist. His interdisciplinary therapy plan included seeing a urologist, pneumatic compression hosiery for his legs, work with a physical and occupational therapists for his gait, strength and balance, speech therapy and nutrition to work on his swallowing and simplifying the number of medications. Adaptations and changes to his home environment included rails to use with stairs and a ramp, a cordless phone for trips to the barn, installation of Lifeline, raised beds for gardening and negotiating with him about use of the tractor and a scooter.

Case 2: Piedmont

Laura Raymon, a 77 year old female came to Piedmont with numerous medical and personal care issues. She suffered from Type II Diabetes, hypertension, chronic heart failure, dementia, severe osteoarthritis with spinal stenosis and degenerative disk disease with sciatica. In addition she had peripheral vascular disease, peptic ulcer, gastro-intestinal bleeding due to an ulcer, proteinuria with renal insufficiency and peripheral neuropathy.

She was on 10 daily medications including three for her blood pressure and heart, two for diabetes, one for stomach, memory, pain and cholesterol. The goals for her improved care included helping her to breathe better when she walks and to enable her to enjoy activities such as bingo and crafts. Her daughters were concerned about her memory and not eating enough and they felt she needed companionship. The plan put in place to address these goals included a monitoring with lifeline, telehealth monitor, installation of steps and rails for her home, increased attention and monitoring of her pharmacy needs and medications, monitoring for depression and to make sure that she stop driving.

Case Study from Siouxland PACE

Maria is a 63 year old Hispanic woman who resides in a rural community with her family and was referred to PACE. Maria is married and lives with her husband, son, granddaughter, and three great grandchildren---one of whom is a new baby. Maria has a history of diabetes, hypertension, obesity, and an injured right shoulder that has been surgically repaired. Because Maria has no health insurance, she receives medical care at the Community Health Center in Sioux City, which is approximately 25 miles from the rural community. Maria had been assisting her husband with peritoneal dialysis four times daily due to his chronic renal failure. Just recently, the peritoneal dialysis treatments have been provided by a cycler unit which allows for the treatment to be provided overnight. Maria
had surgery to repair her shoulder injury but did not complete the therapy visits and has pain and limitation with her shoulder.

Because of the gas prices, and low income---Maria does not always keep physicians appointments and sometimes forgets to take her medication. She is overwhelmed with caring for her husband and worries about finances and medications. Maria recently went to the emergency room for what she describes as a “nervous breakdown”. It appeared that without interventions Maria was headed towards some kind of physically and emotionally crisis.

PACE Services were explained to Maria and her husband and Maria wanted to enroll in the PACE program. The Enrollment Coordinator assisted Maria to apply for Medicaid, which was approved. The PACE interdisciplinary team have completed the comprehensive assessment and approved enrollment into PACE. Primary Care goals are to improve pain management, advance planning and medication management related to diabetes and hypertension. Nursing will assist with medication management and diabetic self care; physical therapy will provide therapy to assist with the shoulder pain and mobility; homemaker services will assist with light housekeeping in her home environment; and a social worker is work on emotional support and assisting with anxiety related to her role in caregiver for her husband and her family. PACE services will utilize the PACE Center two times per week for socialization and caregiver relief. The dietician is assisting Maria on nutrition with her diabetic diet.

PACE contracted with the rural home health provider to assist with her care for nursing and homemaker visits. Siouxland PACE has received a community physician waiver for rural physicians. With that waiver, Maria can receive primary care services in her community from the rural physician. Transportation will be provided to the PACE Center two times per week, which Maria wanted to attend. Through the coordination of the PACE interdisciplinary team and rural health care providers, Maria can meet the needs of this participant as she has not been able to receive services before this time.
**At Home Inc., Oneonta, New York**

**Goal of the Program:** The goal of the program is to increase access to care by enhanced monitoring of health status, improving efficiency of delivering care and providing clinical intervention as conditions warrant to reduce disease associated complications.

**Location:** The At Home Care Inc – Home Care and Telehealth program serves 4 rural counties in south central New York State.

**Population Served:** The program serves primarily an elderly population, typically 81 to 85 years of age, however, the services are need based and can serve newborns through older adults. The typical individual has multiple healthcare conditions including EG heart failure, diabetes, hypertension and cardio-pulmonary disorder.

**Services Provided:** The services provided include case management to support the transition to a home setting, in-home skilled nursing care and home rehabilitation services (e.g. physical therapy, occupational therapy, speech and clinical nutrition), personal care services (home health aides) and disease management programs. Additionally, remote patient monitoring services are available through telehealth.

**Partners:** Groups and agencies who partner with Home Care and Telehealth/At Home Care Inc include: the Office on Aging for meals on Wheels and homemaker support, hospitals for disease management, lifeline service, hospice programs, nursing home without walls program. The Department of Social Services coordinates homemaker services, personal care aides and transportation services for those individuals covered by Medicaid.

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**Case Study from At Home Inc.**

Andy was a 93 year old gentleman admitted to At Home Care Inc. in 2003. He suffered from a multitude of health problems including heart failure, COPD, renal failure, colon cancer, anemia and hypertension. Andy was hospitalized for two lengthy periods during the six month period prior to initiating home telehealth in June 2004. Following admission to telehealth, for the ten month period, Andy required only two hospitalizations. The first hospitalization was unrelated to his cardiac condition, and was due to a surgical repair of a strangulated bowel secondary to metastatic disease; the second admission was for acute exacerbation of HF due to failure to respond to diuretic intervention at home. Since Andy’s final discharge from the hospital, with daily telehealth monitoring the home telehealth nurse noted significant instability in Andy’s condition. Changes were promptly communicated to his physician and frequent medication adjustments became necessary. Based upon telehealth data, standing orders for adjustments in medications were implemented. Despite Andy’s advancing age and deteriorating condition, while on telehealth only one direct unscheduled home nursing visit was required and he required only one re-hospitalization for treatment of his cardiac disease. Without telehealth technology, the physician, nurse and patient agreed that the subtle changes in Andy’s condition would not have been identified early enough to adjust the treatment plan and avoid recurrent hospitalizations. The patient and caregivers were all pleased with the telehealth monitoring as it alleviated many worries. Andy contacted the telehealth care
nurse on multiple occasions “after hours” to report a perceived decline in his respiratory status. With the recommendation to check his oxygen saturation, the nurse was able to verify with Andy that his oxygen level status was within acceptable parameters, his concerns were alleviated and potential Emergency Room visits were avoided. The doctor noted a marked decrease in the frequency of “panic calls” and firmly believed that this technology had not only decreased cost to the health care delivery system but, had also improved the quality of life for this person by enabling him to remain in his preferred setting at home. The patient responded very well to interactive video conferencing. The telehealth monitoring “alleviated many worries” and had a very positive effect on his quality of life. He was able to age in place and live out his last days in his own home.
Jamie's Place, Winthrop, Washington

Goal of the Program: The goal of Jamie's Place is to help residents who are in need to remain in the community by providing the services that they require. And to provide a quality life to older members of the community in a home setting in which they may thrive, enjoy life and demonstrate a good quality of life.

Jamie’s Place is designed after the Green House model, a de-institutionalized effort that restores individuals to a home in the community. It combines small homes with the full range of personal care and clinical services expected in high quality nursing homes. The Green House model of elder care creates an intentional community to support the most positive elderhood and work life possible. To achieve these goals, the model changes the architecture, organizational set-up, staffing patterns and the philosophy of care.

Location: Jamie’s Place is located in Winthrop, Washington in Okanogan County, the largest, most rural and poorest county in the state that is 200 miles from Seattle and Spokane.

Population Served: The facility is licensed as an adult family home and can serve all those adults whose safety can be assured, this excludes those with wandering or unsafe behaviors. Jamie’s place serves a community of 5,000 and has room for six individuals. Jamie’s Place provides services when the family can no longer meet care needs and the older individual does not want to leave the community.

Services Provided: The services are provided in an adult family home operating using the Greenhouse model. The home has a resident manager and on-site and awake staff 24 hours a day with skilled nursing and nurse delegation. The community is involved in providing services as needed including home care, hospice care and physician services. The center coordinates with state funded care managers to assess needs and the appropriate level of care.

Partners: The partners who work with Jamie’s Place include home health agencies, local physicians, case managers and hospice providers. Other partners include emergency response providers, transportation services and the state licensing agencies and ombudsman.

Case Study from Jamie’s Place

Alice B – A 93 year old female

Alice was admitted to Jamie’s place in February 2007 from an Assisted Living facility 45 miles away. Her family was able to drive to see her once a week. Her diagnosis at the time of admittance was Binswanger Dementia, osteoporosis, glaucoma, macular degeneration, congestive heart failure and hearing loss. Her son, Rick,

reported that prior to the move, Alice had been unable to eat with other residents for more than 6 months due to behavior issues. Alice believed that others were eating her food, stealing from her and were annoying to her. Alice had begun to decline in her ability to move around and required assistance to get to the dining room, with toileting, dressing and other ADLs. Her son reported that the original facility she was in would report that she would often go 3-4 days and sometimes longer in her clothes without personal care or changing. Alice refused all bathing assistance and her son would shower her on his
weekly visits to the facility. Alice had been referred to the Ombudsman, mental health, and MD frequently due to increasing frequency of lashing out, inappropriate behavior, and refusal to allow personal care. Her son reported that he had been given notice to move Alice to the local Skilled Nursing Facility due to increased level of care and decline in her medical condition. Rick felt that her prognosis was for only 1-2 months.

Prior to Alice’s admission to Jamie’s Place, Rick and the administrator discussed a plan of care especially around eating, bathing and dressing issues. Dementia behavior management education was presented to staff prior to admission. The care plan included trying to have Alice at the dining table with the other residents. Upon arrival at Jamie’s Place the staff brought Alice to the table for dinner and were unable to take her away. She loved sitting with all the other residents. Some of the differences that her son felt were important included: the staff sitting beside her assisting her and talking to her, a placemat that defined her area, adequate time to complete her meal, and choices she was offered. Alice gained from 78 to 85 pounds. She enjoyed meals and at times even joined in some of the conversations. The staff was able to implement nightly clothing changes with gentle guidance and rarely encountered difficulty getting her changed. Showers continued to be difficult, as Alice “hated” water. However, with consistent attention she did eventually have a weekly shower with staff assistance sometimes with verbal outbursts, always followed by “Thank you and I love you”. Alice was an RN and although she couldn’t remember where or how long she had worked, she would tell us that she knew a thing or two about taking care of patients, and they were “good girls”. Due to close proximity, her son would visit daily for coffee and a sweet roll. He became a visitor to all the residents. He hosted a family visit for all extended family one month prior to her death, when Alice was able to see her grandchildren and great grandchildren; she was like a Queen for that day. Alice passed away in June 2007. Her son reported that he was so happy that during her last 4 months of life she was respected and loved. He felt that she was treated as a person and not a task. Alice taught the staff many lessons in love and patience and she will not be forgotten by those blessed with the time spent with her. Her son, Rick, is now a member of the Board for Jamie’s Place and continues to drop in and visit the staff and other elder residents.