Home and Community-Based Alternatives to Nursing Home Care

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EXECUTIVE SUMMARY

This research was conducted to determine the scope and magnitude of home and community-based care alternatives to nursing homes currently available in rural Pennsylvania and to determine the current need for rural home and community-based care alternatives to nursing homes among specific constituent groups. It also compared the supply of and demand for rural home and community-based (HCB) care alternatives to nursing homes, identified existing and potential gaps in service, and identified current funding issues that enhance or impede the provision of rural HCB care alternatives to nursing homes in Pennsylvania.

The research included all 48 rural counties, as defined by the Center for Rural Pennsylvania, and nine urban counties that border rural counties.

The research found that 77 percent of HCB care providers in the study's 57 counties were nonprofit agencies and budgets among individual HCB care agencies varied significantly. On average, respondent HCB care providers offered 3.8 types of services for consumers, with a reported range of one to eight services.

Respondent agencies and organizations identified a total of 126,461 unduplicated individuals who received HCB care services in 2011. When compared with a Census-based projection of 339,641 viable candidates for HCB care services in Pennsylvania's rural counties, the research determined that 213,180 viable candidates for HCB care services were not being served by the existing service system. The researchers also estimated the current number of rural constituents who could be eligible for HCB care alternatives to nursing homes if such services existed to be 319,450.

The research identified two viable funding models of successful rural home and community-based care alternatives to nursing homes used in other rural states that could be implemented and expanded in Pennsylvania – namely the Minnesota Health Care Home model and the federal PACE program, which is called the Life Program in Pennsylvania.

Policy considerations offered by the researchers focused on funding considerations and addressing the weaknesses in service provision including the following: reviewing and expanding the Life model of service delivery; establishing the Minnesota Health Care Home model of care provision; increasing the availability of HCB care providers in each rural county to alleviate service delivery issues for providers and travel and transportation issues for many elderly and people with disabilities; increasing funding for preventative services that delay institutionalization; addressing barriers to recruiting and retaining HCB care staff; and implementing record keeping standardization.

The Center for Rural Pennsylvania
A Legislative Agency of the Pennsylvania General Assembly

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The Center for Rural Pennsylvania is a bipartisan, bicameral legislative agency that serves as a resource for rural policy within the Pennsylvania General Assembly. It was created in 1987 under Act 16, the Rural Revitalization Act, to promote and sustain the vitality of Pennsylvania's rural and small communities.

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Introduction

America is aging and the anticipated end of life care needs for seniors are growing. According to the 2010 Census, the U.S. experienced a 15.1 percent increase in the age 65 and over population (Werner, 2011). Pennsylvania has the fourth highest population of those age 65 and over in the nation (U.S. Census, 2010). While the 65 and over population has decreased by 0.2 percent (from 15.6 percent to 15.4 percent) in relation to the total state population from 2000 to 2010, the 85 and older population in Pennsylvania increased 0.5 percent during the same time period (U.S. Census, 2010). This is a significant trend and is worth examining as more family and societal support may be required as more of the state's population ages.

The need to understand this phenomenon is even more pressing in rural communities where geographic distance and a more limited base of service providers significantly impact successful aging in place (Melnick, Shanks-McElroy and Chechotka-McQuade, 2004).

In rural Pennsylvania, the elderly are older than the elderly in urban areas. According to data from the 2010 Census, 17 percent of the rural population was 65 years old and older compared to 15 percent of the urban population. From 2000 to 2010, the number of rural seniors increased 5 percent, while the number of urban seniors increased 1 percent.

Rural seniors also are more likely to be poorer and have more health care needs than urban seniors (Hutchison, Hawes and Williams, 2010; Colburn and Bolda, 2001).

Additionally, the rural elderly continue to face a more challenging environment in terms of access to less expensive home and community-based care. Colburn and Bolda (2001) noted that there is a larger supply (per elder) of nursing home beds in rural areas than urban areas, but fewer community-based, in-home services and residential care options. Further, rural seniors also are less likely to have private pay insurance to help offset the cost of home-based care (Hutchison et al., 2010).

Rural elders also have more chronic health conditions, such as arthritis, hypertension, diabetes and heart disease (Hutchison, et.al, 2010), and a higher proportion of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) impairments than their urban counterparts (Hutchison et al., 2010). Therefore, requiring assistance from either family caregivers or institutionalized support, whether through in-home, community-based services, such as meals on

wheels, and/or nursing and personal care or residential care services, such as assisted living or personal care home support, becomes paramount to staying within their homes and in their communities.

The idea that there are large families in rural areas with many available caregivers for both the young and the old, as popularized in the media, is no truer in rural areas than in urban areas (Hutchison et al., 2010). Although there is a national trend toward the reemergence of the multigenerational household, it is largely driven by adult children remaining or moving back in with their parents due to the recent downturn in the U.S. economy. Only about 20 percent of the 65 and older generation live within multigenerational households, a slight increase from 17 percent in the 1990s (Pew Research and Social and Demographic Trends, 2010).

In addition, the barriers of geographic distance to available services combined with accessibility issues and poor health status leave little recourse for rural seniors who want to stay in their own homes. The likelihood of nursing home admission may increase for rural seniors who do not have family and/or social support.

Until the advent of the Medicaid Waiver program, the lack of Medicare coverage for home and community-based services further limited access to services for the rural elderly who lacked disposable income to purchase services. While the Medicaid Waiver program allows for a variety of home and community-based (HCB) services, the availability of services varies from state to state (Hutchison et al., 2010). Rural seniors have a much narrower range of services and confront greater barriers to accessing care than their urban counterparts (Hutchison et al., 2010).

Even with the change in regard to the provision of HCB services through the Medicaid Waiver program, the Medicaid system still supports the predominant structure of the more costly institutionalization of frail seniors. According to the Pennsylvania Homecare Association (2011): "The [Pennsylvania] state budget is constrained by rising Medicaid spending, especially costs relating to long-term cares services and supports (LTSS) for seniors, which accounts for 21.7 percent of the state's general fund expenditures…And although the elderly and adults with disabilities represent just 35 percent of the Medicaid total budget, the cost of their care is disproportionate, representing 69 percent of Medicaid's total budget. These high costs are mostly attributed to nursing home care - the most expensive type of care and least desired."

The development of rural home and community-based services has been limited because of the lack of personal income and/or private insurance to purchase services and the absence of sufficient county and state funds to finance service provision. Nearly 16 percent of those aged 65 and older live below the poverty level (Short, 2010). For seniors who are 85 years and older, the probability of living in poverty continues to increase each year. Boulton (2012) noted that a study by the Employee Benefit Research Institute estimated 14.6 percent of people 85 and older, or roughly one in seven, are living in poverty, and the percentage increased each year between 2001 and 2009.

Throughout the U.S., considerable federal, state, and local dollars have been spent to create a complex continuum of care for the elderly. Keeping older rural adults in the community is more cost effective than institutionalization (Pennsylvania Homecare Association, 2011; Krout, 1994). For this reason, community-based services have developed over time to meet the care, assistance, socialization, and supervision needs of older Americans.

The Pennsylvania Department of Aging (2011) defines home and community-based care services as "services covering a wide range of needs available in communities. These services include: home health care; personal care, such as providing assistance with bathing, dressing, eating, grooming, and toileting; health care support services, such as housekeeping, shopping assistance, laundry and mending; respite care (caregiver relief); transportation and other routine household chores as necessary to maintain a consumer's health, safety and ability to remain in the home; and home-delivered meals prepared at a central location and delivered to a person's home." Each local Area Agency on Aging then defines the specific services from the broad list mentioned above.

Barriers to service development and delivery also exist in rural culture itself. Many of the attitudes that have contributed to survival in rural areas, such as self-reliance, individualism, family orientation and the belief that family should be responsible for care, may also decrease the willingness of the rural elderly to seek and receive assistance and of the rural community to provide services (Hutchison et al., 2010; Connell et al., 1996). Citizens of rural communities may regard HCB services as hand-outs or welfare, misconceptions that create an unfavorable situation for developing and maintaining services (Melnick et al., 2004). Education may play a key role in alleviating these attitudinal barriers. Further research with successful rural HCB care

programs in other states would be beneficial for informing policy considerations in Pennsylvania.

HCB services may be an important addition to the range of services currently available to rural seniors and their families but the absence of program evaluation in rural settings and the continuation of service development barriers in rural areas limits the certainty of this proposition. Hutchison, et al., (2010) noted that the use "of home health services, as measured by the number of visits per health episode, is useful in evaluating rural-urban disparities; however, there is less than unanimity regarding this subject. The mixed results may be attributed to variation in study design, classification of rural and urban areas, and the degree of other factors known to impact home health utilization."

If HCB care services are to be a valuable service to Pennsylvania's rural seniors, it is important to understand how this population is being served from the experience of coordinating agencies, such as local Area Agencies on Aging, the Department of Public Welfare and providers currently in existence.

Goals and Objectives

The study, which was conducted in 2012, had five goals. The first was to determine the scope and magnitude of HCB care alternatives to nursing homes currently available in rural Pennsylvania. To meet this goal, the researchers used the Center for Rural Pennsylvania's definition of "rural" to identify all current providers of rural HCB care alternatives to nursing homes and analyze individual program capacity and the range and types of services offered by existing rural HCB alternatives to nursing homes.

The second goal was to determine the current need for rural HCB care alternatives to nursing homes among two constituent groups: individuals aged 60 years and over, who require assistance with one or more ADL skills, and who cannot, safely, remain independent within a community setting; and persons with disabilities who are under age 60 and who meet the aforementioned criteria. To meet this goal, the researchers compiled the number of unduplicated rural consumers who participated in HCB care alternatives to nursing homes from January 1 to December 31, 2011; and calculated the number of rural constituents awaiting HCB care alternatives to nursing homes from January 1 to December 31, 2011.

The third goal was to compare the supply of and demand for rural HCB care alternatives to nursing homes and identify existing and potential gaps in service. To achieve this goal, the researchers: estimated for each county the current number of rural constituents who would potentially be eligible for HCB care alternatives to nursing homes, if such services existed; calculated county projections of rural constituents who would be viable candidates for HCB care alternatives to nursing homes within 2 – 5 years; compared current and projected demands for rural HCB care alternatives to nursing homes with existing service capacity; and identified those counties where the demand for rural HCB care alternatives to nursing homes exceeded service capacity and/or was expected to exceed service capacity within 2 – 5 years.

The fourth goal was to identify funding issues that enhance or impede the provision of rural HCB care alternatives to nursing homes in Pennsylvania. The researchers: identified funding sources for all rural HCB care alternative program participants from January 1 to December 31, 2011; analyzed the impact of current funding models on the budgeting and operation of rural HCB care alternatives to nursing homes (including impact on equity, accessibility, program quality, and efficiency); reviewed funding models of successful rural HCB care alternatives to nursing homes in other rural states; and formulated policy considerations regarding the removal of financial barriers to the delivery of rural HCB care alternatives to nursing homes.

The fifth goal was to formulate policy considerations regarding the development, growth and maintenance of rural HCB care alternatives to nursing homes in Pennsylvania.

Methodology

This research used a theoretical model consistent with a model for assessing the impact of community-based health care policies and programs for older adults developed by Wan and Ferraro (1991) and used consistently within the literature (Estes and Swan, 1992; Kelley-Gillespie, 2009; Rowan et al., 2011; Rudd, 1996; Van Beveren and Hetherington, 1995). This model measures four major components of community-based service delivery: equity, accessibility, quality, and efficiency (see Figure 1). Equity refers to "the extent that adequate and responsive health services are available for those who are in need of care, irrespective of the ability to pay. The eligibility criteria used in screening clients for a particular benefit are typically considered the indicators of equity because the screening mechanism would ensure that the eligible recipients are truly in need of care" (Wan and Ferraro, 1991). Accessibility refers to "the degree to which a person has adequate

access to care, either for preventive or curative purposes. Barriers to care, such as travel time and distance, clinical office waiting time, appointment time, financial resources, and insurance coverage, can be easily identified and measured so that access-to-care indicators can be compiled" (Wan and Ferrarro, 1991). The characteristic of quality includes three sub-components of service delivery: continuity, acceptability, and effectiveness. Continuity refers to "constancy in providing needed care. Continuity implies that the client's problems are managed without interruption. Continuity of care is important to all service recipients, but especially to older people, who tend to prefer familiar environments and stable social relationships" (Wan and Ferraro, 1991). Acceptability refers to the "extent to which an individual has been given choices in selecting the type of care desired. . . . and the perceived desirability of participation in a program or medical regimen" (Wan and Ferraro, 1991). Effectiveness is a "broad term used to measure the degree to which health service programs have succeeded in meeting personal or organizational goals" (Wan and Ferraro, 1991). Lastly, efficiency is "concerned with whether the same end result can be achieved at a lower cost" (Wan and Ferraro, 1991).

Figure 1: Wan and Ferraro Theoretical Model (1991)

The Wan and Ferraro (1991) model recognizes that the presence and/or absence of an individual program, funding, and client characteristics, along with the interaction of these features, create very specific and unique requirements and demands for rural HCB alternative care programs. As such, this model was beneficial in evaluating services and identifying strengths and weaknesses of the existing rural HCB care network in Pennsylvania.

This study used the Center for Rural Pennsylvania's definition of rural as follows: counties with fewer than 284 people per square mile were designated as rural. Pennsylvania has 48 rural counties, all of which were included in the research. The research also included several urban counties that border rural counties since consumers of HCB services often contract with provider agencies located in an adjacent county who are closer to the consumers' homes. These adjacent urban counties were Berks, Erie, Dauphin, Lackawanna, Lebanon, Lehigh, Luzerne, Northampton, and York.

To identify all current providers of HCB care alternatives to nursing homes, the researchers contacted multiple stakeholders in each of the 57 counties as follows:

- County Area Agencies on Aging (AAA)
- Mental Health/Mental Retardation Base Service Units (MH/MR)
- State Senators (20) and State Representatives (194)
- County Commissioners (177)
- Pennsylvania Adult Day Service Association
- Voluntary Action Center of NEPA
- Diocesan Catholic Charities (5)
- Lutheran Services (18)
- Jewish Family Services (5)
- Senior Centers (302)
- Alzheimer's Association Regional Chapters (4)

The research team compiled a list of 839 stakeholders and contacted them. The list of stakeholders was reduced to 746 as 96 solicitation packages were undeliverable.

These stakeholders were asked to provide the researchers with contact information for any HCB care programs in their county or region. In total, 48 stakeholders returned provider information, representing a 6.4 percent response rate. It is important to note that the stakeholders who participated in this part of the project represented all 48 rural Pennsylvania counties.

The 48 stakeholders identified 555 HCB care providers. After follow up, the total potential participants decreased to 466 as some agencies did not meet the criteria for this study (i.e., personal care homes, assisted living facilities, nursing homes, Early Intervention agencies, etc, that were not HCB care alternative

Table 1: Total Number of HCB Care Providers Identified by County

County	Identified HCB Care Alternative Providers
Adams	1
Armstrong	17
Bedford	3
Berks *	102
Blair	52
Bradford	16
Butler	6
Cambria	3
Cameron	0 (5 HCB in McKean county provide services here)
Carbon	20
Center	1
Clarion	0
Clearfield	1
Clinton	0
Columbia	0
Crawford	10
Dauphin *	42
Elk	0 (5 HCB in McKean county provide services here)
Erie *	1
Fayette	7
Forest	0
Franklin	28
Fulton	0 (28 HCB in Franklin County provide services here)
Greene	0 (29 HCB in Fayette and Washington counties provide services here)
Huntingdon	1
Indiana	19
Jefferson	1
Juniata	0
Lackawanna *	26
Lawrence	4
Lebanon *	0
Lehigh *	33
Luzerne *	6
Lycoming	0
McKean	5
Mercer	1
Mifflin	1
Monroe	0
Montour	0
Northampton *	4
Northumberland	11
Perry	0
Pike	0
Potter	0
Schuylkill	4
Snyder	0
Somerset	4
Sullivan	0 (18 HCB in Bradford and Tioga counties provide services here)
Susquehanna	18
Tioga	2
Union	0
Venango	0
Warren	0
Washington	22
Wayne	0
Wyoming	0 (6 HCB in Luzerne county provide services here)
York *	12
TOTAL Unduplicated HCB Care Providers	466

Note: * Urban counties that serve rural individuals. Data source: Current study.

providers). The total number of HCB care providers in the 57 study counties is shown in Table 1.

The researchers then mailed a survey package to the identified HCB care programs. Data collected from the survey were to measure program equity, accessibility, quality, and efficiency. Equity features that were assessed included eligibility criteria for participation in the programs. Accessibility was assessed according to funding sources for services; waiting list size, status, and longevity; and identification of under-served areas/communities. Program quality was evaluated according to continuity of services (such as average duration of program participation, and numbers of staff providing in-home services during an average week), acceptability of services by clients (such as barriers to service use related to perceptions of undesirability of participation), and program effectiveness (such as longevity of staff and overall outcome assessment of services). Efficiency was evaluated through comparison of program cost per client with demonstrated nursing home costs for the same period. Regarding client characteristics, aggregate information was collected regarding the following: total unduplicated clients; age; gender; living arrangements (alone, with family, etc); average length of time awaiting participation in services; and average length of program participation in months.

The survey sample size was reduced to 349, as 117 survey packages were returned as undeliverable. In spite of protracted and ongoing follow-up with agencies by the research team, only 120, or 2.9 percent, of the sampled agencies returned completed surveys. While the margin of error for this data is +/- 30.6, it should be stressed that these data were collected for inferential testing and to corroborate program and funding data from the AAAs, MH/MR units, and the Department of Public Welfare (DPW).

The researchers created a statistical database for compiling the aggregate equity, accessibility, quality, efficiency, and client characteristic data.

During the preparation of this research, the researchers held informal discussions with representatives from the AAAs, the Pennsylvania Home Care Association, and other stakeholder organizations. They found there were highly divergent estimates of

eligible rural HCB program participants. To develop more concrete and consistent client characteristic statistics with which to compare the study data, the researchers used 2010 Census data for each county, and documented the total numbers of individuals who met the study criteria. From these total numbers, the researchers estimated for each county the proportion of individuals who required assistance with one or more ADL task. They then used the findings from the Pennsylvania Department of Aging's report, Pennsylvania State Plan on Aging, 2008-2012, which indicated that 39.3 percent of eligible individuals may be considered as viable candidates for HCB care services. The researchers used this rate to calculate county projections of rural constituents who would be viable candidates for HCB care alternatives to nursing homes.

The researchers also used data from the AAAs, MH/MR units, DPW and the program survey results to delineate strengths and weakness of the current rural network of alternative care programs and explored best practices in other rural areas to develop policy considerations.

Table 2: Total Clients Served by Individual Programs

Program Type	Total Clients Served 2011	% of Total Unduplicated Clients Served by Program
Information and Assistance	66,048	52.2%
Transportation	41,976	33.2%
Senior Centers	35,676	28.2%
Congregate Meals	29,852	23.6%
Home Delivered Meals	16,652	13.2%
Medication Management	13,207	10.4%
Assessment Services	9,501	7.5%
Personal Care	7,911	6.3%
Home Support Services	4,692	3.7%
Care Management	4,380	3.5%
Personal Assistant Services	3,059	2.5%
Adult Protective Services	2,991	2.4%
Personal Emergency Response Systems	2,897	2.3%
Medical Supplies/Equipment	1,134	0.9%
Adult Day Services	941	0.7%
Elderly Law Project	782	0.6%
Family Caregiver Support Program	721	0.6%
Visitation/Telecare	599	0.5%
Representative Payee Services	570	0.4%
Nursing Home Transition Services	543	0.4%
Consumer Reimbursement	413	0.3%
Guardianship Services	375	0.3%
Aging Waiver Program	353	0.3%
Attendant Care	140	0.1%
Pre-Vocational Services	135	0.1%
Domiciliary Care	50	0.03%
Respite Services	49	0.03%
Competitive Employment Services	35	0.02%
Ombudsman Program	18	0.01%
Environmental Modifications Program	11	0.01%

Note: Multiple agencies were unable to report complete service use due to a lack of agency record keeping. While services that require medical necessity for referral and payment by a third party payer (i.e., Medicare, AAA, private insurance) were well-documented, services provided as an add-on for consumers already receiving medically necessary services (i.e., personal care, home support, attendant care, etc.) were only sporadically counted in service rosters by many agencies. Data source: Current study.

Results

Total Unduplicated Consumers in 2011

According to the research findings, as of January 23, 2013, the total number of unduplicated clients served by AAAs, MH/MR units and individual service providers was 126,461. The total unduplicated clients over age 60 was 88,663 and the total under age 60 was 31,062 (6,736 of the total unduplicated clients are not included in the under 60 or over 60 age group breakdown because reporting agencies were unable to provide data at that level. Specifically, those agencies did not collect data regarding client age.)

Range and Types of Services Offered by HCB Care Providers in 2011

HCB provider respondents offered a variety of services for consumers as detailed in Table 2.

On average, participating HCB care providers reported offering 3.8 types of services for consumers, with a range of one to eight services. Seventy-seven percent of HCB providers were nonprofit agencies and individual

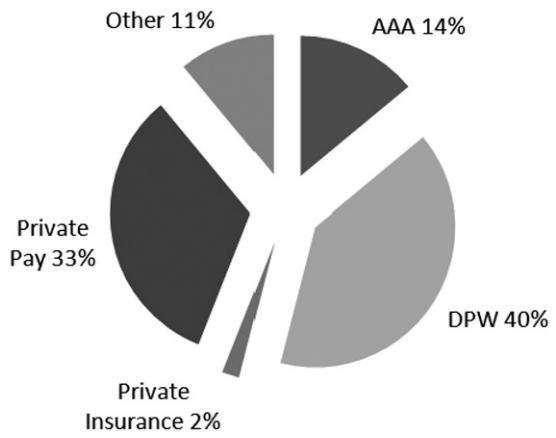
HCB care provider budgets varied significantly with the following data noted:

Budget Prior Year (2011)
Mean = $3,285,887
Range=$57,142 - $20,200,000

Proposed Budget Current Year (2012)
Mean = $3,296,053
Range= $63,965- $20,200,000

The funding sources for services provided in 2011 are summarized in Chart 1 on Page 8.

Chart 1: Funding Sources for Services, 2011



Data source: Current study.

Equity, Accessibility, Quality and Efficiency of Services Provided

Equity

As summarized in Table 1, 466 HCB providers were identified as serving consumers in the study area. Eighty-six, or 18.5 percent, cover multiple counties with lengthy distances in between. Fifteen counties (26.8 percent) had no identifiable HCB that provided services, and an additional 12.5 percent had only one identifiable HCB. These findings raise some important concerns regarding the adequacy of available services for individuals and families who reside in counties with few or no HCB providers.

Eligibility criteria as a measure of equity were assessed for individual programs provided by HCB participants. In addition to meeting the age criteria for participation (over age 60 for aging services and over age 18 for MH/MR related services), several additional eligibility criteria were noted in the qualitative data collected. Most notably was the payment source: if the individual was not eligible for an established service, such as home health (paid by Medicare or private insurance), or did not meet the requirements for a service provided by the AAAs, the person would have to pay privately.

The research results strongly indicate that most of the consumers served received services paid by some form of government funding. To be eligible for government-paid services, recipients must require medically necessary services. This form of service eligibility is commonly referred to as the "medical model," a community health care service providing non-acute care patterned after the diagnosis/treatment model of physicians (Melnick et al., 2004). Therefore eligibility for service access often hinges on a documented need for intensive, skilled nursing services. Consumers who require only non-medically based services designed to support independence and the completion of ADL are ineligible to receive HCB services, such as adult day services, personal care, and home support, unless they possess private funds to pay for services. This finding suggests that all Pennsylvania seniors and those under 60 with a disability must be significantly impaired to receive supported/funded services. These criteria have the potential to put consumers at risk. The consumers' health may deteriorate as they await services that may never materialize and thus they may require institutionalization. However, those consumers who can afford to pay privately have a better chance of remaining in their home for longer periods.

Accessibility

As noted previously, 466 HCB providers were identified as servicing consumers in the study catchment area. Eighty-six (18.5 percent) providers cover multiple counties with lengthy distances in between. Fifteen counties (26.8 percent) had no identifiable HCB care providers and an additional 12.5 percent had only one (1) identifiable HCB care provider. These findings raise

Table 3: Waiting List Occupancy by Program Type and Length of Duration (N = 1,522)

Program	Total Individuals on Program Waiting List as of 1/1/2012	Mean Duration in Months	Range of Duration in Months
Medication Management	668	4 months	1 month – 12 months
Personal Care	545	3 months	1 month – 12 months
Transportation	267	3 months	1 month – 12 months
Home Support Services	177	3 months	1 month – 12 months
Home Delivered Meals	121	Not reported	Not reported
Representative Payee	120	Not reported	Not reported
Personal Emergency Response System	93	Not reported	Not reported
Medical Equipment/Supplies	92	Not reported	Not reported
Family Caregiver Support Program	72	Not reported	Not reported
Personal Assistance	50	Not reported	Not reported
Adult Day Services	43	4 months	1 month – 12 months
Employment Services	29	Not reported	Not reported
Attendant Care	14	3 months	1 month – 12 months
Congregate Meals	12	4 months	1 month – 12 months
Respite Services	10	Not reported	Not reported
Guardianship	5	Not reported	Not reported
Senior Centers	1	Not reported	Not reported
TOTAL	2,319		

Data source: Current study.

some important concerns regarding the accessibility of available services for individuals and families who reside in counties with minimal or no HCB care providers. With an increased need to include travel time as a component of care scheduling, and as an important factor in staff recruitment, retention, and compensation, individuals and families who reside in counties without an adequate supply of HCB care providers may be unable to access services when staff cannot be dispatched efficiently and cost effectively from a distant geographic locale.

Waiting list occupancy for services was also used at a measure of program accessibility. The research found that, in 2011, 83 unduplicated individuals under age 60 and 1,439 unduplicated individuals over age 60 occupied a service waiting list, for a total of 1,522 individuals. Study participants were also asked to identify the total number of individuals on waiting lists for individual programs, along with average duration of waiting list occupancy and range of months spent waiting for services. The data are summarized in Table 3.

Not surprisingly, those services with the largest waiting lists, including personal care services, home support services, and medication management, are smaller programs with the fewest unduplicated clients. Because the individuals on waiting lists for those services do not require skilled nursing services, which would provide a gateway to non-medically necessary services, agencies do not have adequate resources to make those services available in the numbers they are needed or with the funding sources available to individuals and families in the community. The length of time consumers wait for services could not be evaluated since many services are not consistently recorded by agencies. This information would have helped to understand the true scope of individuals waiting for services but its absence does not detract from the study findings.

Lastly, agencies reported problems with recruitment and retention of staff due to several consistent issues as follows: undesirability of work duties, need for evening and overnight work hours, long travel requirements to reach clients' homes, low reimbursement rates for staff, and limited availability of full-time work due to a lack of funding for non-medically based services.

Qualitatively, personal care service providers reported barriers to recruiting and retaining staff because of less than desirable work duties, travel requirements in rural areas, and evening and overnight work hours. Agencies that provide congregate meals indicated that staff recruitment and retention were negatively impacted by uncompetitive wages, and personal assistance service providers experienced difficulty retaining staff because of limited work hours. This concern is compounded by the same lack of desirable work duties and travel requirements cited by personal care service providers. This finding is consistent with research conducted by Melnick et al. (2004).

Table 4: Program Participation Duration for Clients

Program	Mean Participation Duration in Months	Range of Participation Duration in Months
Medication Management (n = 13,207)	32	12 months – 48 months
Personal Care (n =7,911)	27.7	9 months – 48 months
Transportation (n = 41,976)	24	1 month – 48 months
Home Support Services (n = 4,692)	48	1 month – 48 months
Home Delivered Meals (n = 16,652)	Not reported	Not reported
Representative Payee (n = 570)	Not reported	Not reported
Personal Emergency Response System (n = 2,897)	Not reported	Not reported
Medical Equipment/Supplies (n = 1,134)	Not reported	Not reported
Family Caregiver Support Program (n = 721)	Not reported	Not reported
Personal Assistance (n = 3,059)	30	12 months – 48 months
Adult Day Services (n = 941)	18	12 months – 30 months
Employment Services (n = 0)	Not reported	Not reported
Attendant Care (n = 140)	13.5	1 month – 42 months
Congregate Meals (n = 29,852)	27	12 months – 42 months
Respite Services (n = 49)	Not reported	No reported
Guardianship (n = 375)	Not reported	Not reported
Senior Centers (n = 35,676)	Not reported	Not reported

Data source: Current study.

Quality

Quality includes three sub-components of service delivery: continuity, acceptability, and effectiveness. Continuity of care is important to all service recipients, but is especially important to older people, who tend to prefer familiar environments and stable social relationships (Wan and Ferraro, 1991). Duration of program participation was used to assess continuity and participants were asked to identify the average duration of participation for each program, along with the range of participation duration for all clients (See Table 4).

For programs reporting participation duration, it appeared that once an individual began to receive services, he/she remained on the agency caseload for a minimum of 13.5 months. This indicates a positive level of continuity of care. Respondents were also asked to provide the average number of unduplicated staff who

provided care for a specific client within a given week. However, respondents were unable to provide the information because records were not available.

Respondents were asked to identify barriers to client service use related to problems with perceived desirability issues. HCB care providers indicated a disconnect between consumer and family perceptions of service need that negatively impacts service use. In particular, personal care service providers and adult day service providers noted that while family members may want a client to have services, the client does not recognize the need for services and is not willing to participate.

In addition, HCB care providers reported that both family and consumers were deterred from using services due to perceptions of undesirability related to the presence of severely impaired peers in programs like adult day services. Lastly, as a more generalized observation, respondents reported that in-home services were regarded as an invasion of privacy for some consumers.

Efficiency

Since this study could not compare outcomes between HCB services to nursing home and other institutionalized care, the research could not address the issue of efficiency. Additionally it would have been difficult to compare service providers across counties within the confines of this study since issues, such as geographic location and competition between providers, impact service provision costs. A consideration would be to further explore the question of efficiency in future research.

Table 5: Total Non-Institutionalized Individuals Eligible for HCB Care Due to Disability and/or Age by County.

County	Non-Institutionalized Individuals with A Disability 21-64 Years	Non-Institutionalized Individuals 65+ Years	Total Non-Institutionalized Individuals Eligible for HCB Due to Disability and/or Age
Adams	6,191	15,162	21,353
Armstrong	6,583	12,371	18,954
Bedford	4,170	9,318	13,488
Blair	9,772	20,880	30,652
Bradford	4,865	10,696	15,561
Butler	9,281	26,811	36,092
Cambria	12,237	26,100	38,337
Cameron**	187	1,086	1,273
Carbon	5,921	11,312	17,233
Center	7,093	16,610	23,703
Clarion	2,857	6,388	9,245
Clearfield	5,097	12,325	17,422
Clinton	2,902	6,217	9,119
Columbia	3,462	10,318	13,780
Crawford	8,028	14,131	22,159
Elk	2,021	5,849	7,870
Fayette	14,906	23,738	38,644
Forest**	331	1,378	1,920
Franklin	8,060	24,025	32,085
Fulton**	542	2,544	3,086
Greene	3,063	5,717	8,780
Huntingdon	3,475	7,116	10,591
Indiana	5,820	13,430	19,250
Jefferson	3.545	7,884	11,429
Juniata	1,672	3,807	5,479
Lawrence	6,471	16,556	23,027
Lycoming	8,283	18,245	26,528
McKean	3,916	6,840	10,756
Mercer	9,860	20,443	30,303
Mifflin	3,781	8,267	12,048
Monroe	12,565	21,416	33,981
Montour**	682	3,395	4,077
Northumberland	6,816	16,678	23,494
Perry	3,232	6,120	9,352
Pike	4,640	9,214	13,854
Potter**	630	3,403	3,641
Schuylkill	12,799	25,493	38,292
Snyder	2,142	5,918	8,060
Somerset	5,854	13,918	19,772
Sullivan**	238	1,557	1,795
Susquehanna	3,723	7,625	11,348
Tioga	3,185	7,399	10,584
Union	1,956	6,248	8,204
Venango	4,883	9,499	14,382
Warren	3,138	7,398	10,536
Washington	15,581	35,154	50,735
Wayne	3,854	9,812	13,666
Wyoming	2,466	4,440	6,906
TOTAL	252,776	560,251	813,027

** For rural counties where ACS data were unavailable, population data for the total 18-64 years and 65+ years age groups were extracted from Decennial Census Data 2010 (U.S. Census Bureau). The Pennsylvania state average for individuals aged 18 – 64 with a disability (6.2%) and the Pennsylvania state average for individuals age 65+ (21.2%) were then used to identify county constituents eligible for HCB care eligibility. Data source: American Community Survey, 2008-2011.

Comparison of Supply of and Demand for Rural HCB Care Alternatives to Nursing Homes and Identification of Existing and Potential Gaps in Service

To analyze the supply of and demand for rural HCB care alternatives, the researchers estimated for each county the current number of rural constituents who could be eligible for HCB care alternatives to nursing homes if such services existed. The researchers used data from the 2008-2011 American Community Survey (U.S. Census, 2012). The researchers did not include the nine adjacent urban counties in this part of the analysis, and, due to the HCB care focus of this study, only included non-institutionalized persons with disabilities, age18-64 years, and non-institutionalized individuals over the age of 65 who are potential HCB care consumers in the analysis. Table 5 shows the total non-institutionalized individuals eligible for HCB care due to a disability or age.

Table 6: Projection of Total Viable Candidates for HCB Services by County

County	Total Non-Institutionalized Individuals Eligible for HCB Due to Disability and/or Age	Total Viable Candidates for HCB Care Services (calculated at rate of 39.3%)
Adams	21,353	8,392
Armstrong	18,954	7,449
Bedford	13,488	5,301
Blair	30,652	12,046
Bradford	15,561	6,115
Butler	36,092	14,184
Cambria	38,337	15,066
Cameron	1,273	500
Carbon	17,233	6,773
Center	23,703	9,315
Clarion	9,245	3,633
Clearfield	17,422	6,847
Clinton	9,119	3,584
Columbia	13,780	5,416
Crawford	22,159	8,708
Fayette	38,644	15,187
Forest	1,920	755
Franklin	32,085	12,609
Fulton	3,086	1,213
Greene	8,780	3,451
Huntingdon	10,591	4,162
Indiana	19,250	7,565
Jefferson	11,429	4,492
Juniata	5,479	2,153
Lawrence	23,027	9,050
Lycoming	26,528	10,426
McKean	10,756	4,227
Mercer	30,303	11,909
Mifflin	12,048	4,735
Monroe	33,981	13,355
Montour	4,077	1,602
Northumberland	23,494	9,233
Perry	9,352	3,675
Pike	13,854	5,445
Potter	3,641	1,431
Schuylkill	38,292	15,049
Snyder	8,060	3,168
Somerset	19,772	7,770
Sullivan	1,795	705
Susquehanna	11,348	4,460
Tioga	10,584	4,160
Union	8,204	3,224
Venango	14,382	5,652
Warren	10,536	4,141
Washington	50,735	19,939
Wayne	13,666	5,371
Wyoming	6,906	2,714
TOTAL	813,027	319,450

Data estimates based on data provided by the ACS 2008-2011 and U.S. Census Bureau, 2010.

To project the number of "viable candidates" for HCB care programs, the researchers used the Pennsylvania Department of Aging's (Pennsylvania State Plan on Aging, 2008-2012) rate of 39.3 percent of eligible individuals that are likely to use HCB care services at any particular time (See Table 6).

For the study, respondent agencies and organizations identified a total of 126,461 unduplicated individuals who received HCB care services in 2011. When compared with ACS and Census-based projections of 319,450 viable candidates for HCB care services in Pennsylvania rural counties, the researchers found that 192,989 viable candidates for HCB care services are unserved by the existing service system.

The researchers used Census data to calculate county projections of rural constituents who will be viable candidates for HCB care alternatives to nursing homes in the coming years. The original intent of the study was to provide projections within 2-5 years, but the researchers were able to provide projections to 2030 (See Table 7 on Page 12).

Conclusions

Strengths and Weaknesses of the Current Rural HCB Care Network

The presence of 466 HCB care alternative providers, with an estimated service ratio of 9.7 HCB care agencies per county, to provide services in Pennsylvania's 48 rural counties may initially be regarded as a strength. However, 15 counties (26.8 percent) had no identifiable HCB care provider that offered services, and an additional 12.5 percent had only one identifiable HCB care provider. While not necessarily indicative of inadequate service, these findings raise some important concerns regarding the sufficiency of available services for individuals and families who reside in these counties. The distances that home health workers must travel to reach consumers negatively impacts efficiency as more time is spent on the road. To combat this weakness, providers must either hire more workers, which increases costs, or serve fewer individuals. Given the problems with recruiting and retaining staff, serving fewer individuals is the most likely outcome.

A second strength involves the range of services offered by HCB care providers in rural Pennsylvania counties. In general, HCB care agencies provided anywhere from one to eight services. However, given the eligibility criteria for services, which are based on a documented need for intensive skilled nursing services, consumers who require only non-medically based services designed to support independence and the completion of ADL are ineligible to receive HCB care services. This finding suggests that rural seniors and those under 60 with a disability must be significantly impaired to access the broad spectrum of services. This puts these consumers at significant physical risk as they

Table 7: County Projections of Viable HCB Care Alternative Participants 2010-2030

County	Viable Candidates for HCB 2010	Projected % Change 2010-2020	Projected Viable Candidates for HCB 2020	Projected % Change 2020-2030	Projected Viable Candidates for HCB 2030
Adams	8,392	8.6%	9,113	5.9%	9,651
Armstrong	7,449	-3.3%	7,203	-3.2%	6,973
Bedford	5,301	1.5%	5,381	0.4%	5,403
Blair	12,046	-5.2%	11,420	-5.6%	10,780
Bradford	6,115	-2.1	5,987	-1.1	5,921
Butler	14,184	8.6%	15,404	8.1%	16,652
Cambria	15,066	-5.7%	14,207	-5.7%	13,397
Cameron	500	0.0%	500	0.7%	504
Carbon	6,773	6.3%	7,200	3.8%	7,473
Center	9.315	6.4%	9,911	7.0%	10,605
Clarion	3,633	-2.3%	3,549	-2.0%	3,478
Clearfield	6,847	-1.4%	6,751	-1.9%	6,623
Clinton	3,584	-4.9%	3,408	-3.7%	3,282
Columbia	5,416	4.0%	5,633	4.3%	5,875
Crawford	8,708	-2.1%	8,525	1.8%	8,678
Elk	3,093	-8.7%	2,824	-7.5%	2,612
Fayette	15,187	-4.3%	14,534	-5.1%	13,793
Forest	755	10.5%	834	8.5%	905
Franklin	12,609	4.5%	13,176	5.4%	13,888
Fulton	1,213	7.9%	1,309	6.4%	1,393
Greene	3,451	-1.1%	3,413	-2.9%	3,314
Huntingdon	4,162	1.4%	4,220	-0.9%	4,182
Indiana	7,565	-9.1%	6,877	-7.5%	6,361
Jefferson	4,492	-1.7%	4,416	-2.7%	4,296
Juniata	2,153	3.6%	2,231	3.9%	2,317
Lawrence	9,050	-4.0%	8,688	-2.9%	8,436
Lycoming	10,426	-2.3%	10,186	-2.6%	9,921
McKean	4,227	-4.7%	4,028	-4.0%	3,867
Mercer	11,909	1.1%	12,040	1.3%	12,196
Mifflin	4,735	0.5%	4,759	-0.8%	4,721
Monroe	13,355	25.1%	16,707	22.8%	20,516
Montour	1,602	-1.3%	1,581	0.0%	1,581
Northumberland	9,233	-0.4%	9,196	-0.7%	9,132
Perry	3,675	1.8%	3,741	1.2%	3,786
Pike	5,445	37.0%	7,460	29.4%	9,653
Potter	1,431	-0.6%	1,422	-2.7%	1,384
Schuylkill	15,049	-0.4%	14,989	-0.2%	14,959
Snyder	3,168	1.9%	3,228	-0.1%	3,225
Somerset	7,770	-1.6%	7,646	-1.1%	7,562
Sullivan	705	-0.4%	702	-0.4%	699
Susquehanna	4,460	31.0%	5843	37.7%	8,045
Tioga	4,160	-1.5%	4,098	-0.2%	4,089
Union	3,224	8.7%	3,504	5.4%	3,694
Venango	5,652	-4.1%	5,420	-4.6%	5,171
Warren	4,141	-8.5%	3,789	-8.1%	3,482
Washington	19,939	2.2%	20,378	0.9%	20,561
Wayne	5,371	17.0%	6,284	13.8%	7,101
Wyoming	2,714	-10.2%	2,437	-12.3%	2,137
TOTAL	319,450		326,152		334,274

Note: Given the lack of change that is predicted for individuals aged 21 – 64 with disabilities, the numbers of those individuals in each county are expected to remain constant. Projected changes apply to the 65 and over population only. Data source: U.S. Census Bureau's Decennial Censuses and Pennsylvania State Data Center.

wait for services that may never materialize and thus may require institutionalization.

Compounding difficulties in accessing non-medically based services is the funding model for services that exist in Pennsylvania. Nearly 16 percent of rural seniors live below the poverty level (Short, 2011). In Pennsylvania rural counties, 54 percent of HCB care services provided to individuals over age 60 and individuals under age 60 with a disability were funded by payments through the Departments of Aging and Public Welfare. While duration of participation in HCB care programs is lengthy once initiated (a minimum of 13.5 months in the study sample), for many consumers, services are only available on a private-pay basis. Although this study did not specifically collect data regarding costs of services, service funding suggests an overreliance on private pay for all non-medically based services. This excludes a large proportion of rural consumers who would be considered viable HCB care program participants who lack disposable income to purchase services.

Geographic distance for seniors and individuals with disabilities to travel to community-based services is another weakness in the rural care network. Many seniors and individuals with disabilities may willingly opt out of services if the travel time is too long or if transportation is not available (Melnick et al., 2004).

In reviewing the conclusions of this research, study limitations must be kept in mind. While data collection with individual HBC care providers was completed to provide corroboration of the data provided by AAAs, MH/MR units, and DPW, the sample size of these participants was a concern. However, the strong level of agreement among all of the data helped assure the reliability of the data. Input from larger numbers of HCB care providers would have provided important new insights into the models of service delivery and payment that currently exist.

Funding Models of Successful Rural HCB Care Alternatives to Nursing Homes in Other States

A review of the available literature regarding successful funding models for rural HCB care alternatives to nursing home care within other rural states was scarce in terms of successful model development. While some successful models are discussed in the literature, which is presented below, more often the barriers to effective service delivery are presented. It appears, from this review, that Pennsylvania is not alone it in its quest to provide affordable, reliable and consistent HCB services to the rural elderly and individuals with disabilities.

The report, Serving Older Adults in Rural North Carolina: Meeting the Challenge (Bearson, 2000), noted that the kinds of services that are lacking in rural areas are "those that delay or eliminate the need for institutionalization (such as care coordination or in-home care beyond Medicare's post hospital discharge limit)." One reason cited for this lack of services is that rural governments tend to have fewer resources available to fund appropriate services.

Nelson and Stover Gingerich (2010) provided further clarification of the results of the North Carolina study. They noted that small, rural providers of home-based care are finding it more difficult if not impossible to remain financially viable in the current regulatory environment. Many of these rural-based agencies have lower operating margins and thus are more susceptible to the general downturn in the economy. Further, they have "much lower operating margins than urban agencies" (Nelson and Stover Gingerich, 2010). A major impact in the provision of services appears to be the funding changes within the Medicare payment system.

According to Nelson and Strover Gingerich (2010), "decreasing Medicare reimbursement and increasing regulatory requirements have had a significant impact on rural home care agencies that have already been struggling with lower profit margins. At the time the Prospective Payment System was implemented in 2000, rural home care agencies enjoyed a 10 percent rural add-on to Medicare payments. This add-on dropped to 5 percent in 2004 and was eliminated in 2006… because of this, many rural home care agencies are finding that they simply cannot afford to provide services to outlying areas. The expense associated with covering large service areas with limited staff can be daunting. The rising cost of mileage and travel time is glaring, but the loss of productivity while staff members are traveling further compounds the expense. The current economic environment promotes shrinking service areas and an increasing number of rural individuals without access to the home care services they need to remain independent."

A study conducted by the Minnesota Department of Health (2009) noted that health care in the U.S. is highly fragmented and overly reliant on specialized care, that care is often excessive and inefficient, and that the payment system creates incentives for procedures rather than wellness and prevention. Minnesota set out in 2008 to redesign health care in general and in particular to rural areas. Minnesota's response came in the form of the "Health Care Home" (Minnesota Department of Heath, 2009). The Health Care Home first emerged as a model of care for children in 1967. It has thus been adapted to encompass an elderly, rural population in the Minnesota model.

The major principles of this model are, "physician directed medical practice; personal doctor for every patient; comprehensive; coordinated and family-centered; accessible, continuous and high quality; compassionate and culturally effective and; a payment system recognizing the added value for patients" (Minnesota Department of Heath, 2009). This model puts the patient or service recipient at the center of the care process where they remain the primary focus.

The main reasons the Minnesota Department of Health felt that this model would hold advantages in rural areas and for elders living in in those areas include:

- Rural physicians are trained and experienced in family practice.
- Rural communities are concentrated. Patients are less scattered among multiple delivery systems.
- Rural health care delivery often established teams of care providers.
- Many rural communities are involved and engaged in health care access and delivery (Minnesota Department of Heath, 2009).

Conversely the challenges in rural areas that can potentially negatively impact the Health Care Home model can also be those that have the potential to positively impact services. Some of these include:

- Workforce: rural communities face a decline in trained service providers.
- Care Coordination: the delivery of health care services involves many disciplines (e.g., clinics, hospitals and emergency medical technicians), and organizations (e.g., clinics, hospitals, nursing homes and local public health) making it important to pursue a coordinated approach. Care coordination can be challenging for rural communities with many small, independent providers, scare resources, and health care services that must cover vast geographical areas.
- Technology: electronic health records (EHR's) and telehealth services are being used more frequently, bridging the geographic distance that can interfere with access to health care. However, the rural health care infrastructure is under-resourced and not all rural health providers have the financial

capacity to fully implement EHR's or exchange information electronically.

- Reimbursement: current payment policies do not adequately reimburse for many activities to offer care coordination services. Instead, the existing payment system, both private and government, pays for health care services on an episodic, visit-related basis, having the perverse effect of rewarding volume over prevention and collaboration (Minnesota Department of Heath, 2009).

In May 2012, HealthLeaders Media reported that Minnesota's primary care delivery model, which began in July 2010, grew to 170 health care homes, with 1,764 clinicians at the end of 2011. These state-certified health care homes provided care to more than 2 million of Minnesota's 5.3 million residents. That patient population included more than 135,000 Medicaid enrollees, or roughly 18 percent of those in the program who used primary care. In part, that was because chronically ill Medicaid enrollees were incentivized to join health care homes through medical assistance payments of $10 to $60 a month, depending upon the complexity of their health issues (HealthLeaders Media, 2012).

In a summit conducted by New York State in 2007, participants identified areas of concern that cut across a number of identified challenges facing older rural residents of the state. The areas of concern included: fragmentation, inflexibility, and multiplicity of New York state funding sources; the workforce crisis in long-term care and aging services; the economic need of rural elders and their communities; the lack of or inadequate public transportation; affordable and accessible education/training opportunities; the development of a rural technology infrastructure; and the inability to recruit, train and retain volunteers (Ithaca College Gerontology Institute, Rural Aging Summit, 2007).

In addition, the need for more funding to support current service providers in rural areas was identified as a major concern, however what was also noted was the need for a better use of existing services and programs within the state (Ithaca College Gerontology Institute, Rural Aging Summit, 2007).

Furthermore, the summit members identified two major problem areas as they relate to social and support services within rural areas of New York State: funding for aging services is fragmented and restrictive and has not kept up with the increasing needs; and a shortage of adequately trained, well-supported staff to work with seniors exists. Summit participants offered the following recommendations to address these issues as follows: coordinate and increase flexible state funding for social and supportive services to enable aging in place; and create incentives to attract, train, and retain professional and direct care workers serving rural elders (Ithaca College Gerontology Institute, Rural Aging Summit, 2007).

As a follow-up to the summit, the director of the New York State Office for the Aging (NYSOFA) hosted a Regional Community Empowerment Conference Call in 2009 to express interest in offering technical assistance in support of local communities for the development of livable communities for aging in place starting in the fall of 2009. Suggested methods included holding regional mini-summits to convene interested leaders and participants who could play a role in fostering local activities and initiatives, and establishing a working group or steering committee, either statewide or regionally, that NYSOFA could work with to help facilitate action and coordinate activities across regions.

The actions in New York State can provide Pennsylvania with a model for response to rural aging issues as many of the identified challenges that impact rural older residents there also are experienced in the commonwealth. The noted challenges of rural distances as they relate to service provision, inadequate public transportation and the need for more funding to support providers of rural services transcend state lines.

In a response to the demands to establish cost-effective care for the elderly in this country, the federal government created the Rural Program of All-Inclusive Care for the Elderly (PACE) Pilot Grant Program. The program was established by Congress under the Deficit Reduction Act of 2005 and administered by the Centers for Medicare and Medicaid Services (CMS) and provided 15 providers with start-up funds to develop PACE organizations serving rural elders. This program is an integrated, acute and long-term care model for frail, disabled adults living in the community. To avoid confusion with the medication reimbursement PACE program in Pennsylvania, the program is known as LIFE Centers in Pennsylvania. One of the initially funded sites was Geisinger Health System Foundation in Danville, Pa., which currently operates Life Geisinger in Scranton, Pa. Pennsylvania has 17 Life (PACE) program providers that operate 30 centers in 18 counties (Personal Communication, Office of Long Term Living, Pennsylvania Department of Public Welfare, January 29, 2013).

Petigara, Tanaza and Anderson (2009) note, "…the growth of PACE has been much slower than expected. … By 2008 only 61 PACE programs were operating in 29 states. While several million adults are potentially eligible for PACE, only 17,000 are enrolled." Further, they go on to discuss barriers to the expansion of PACE programs throughout the country. These barriers include the following: PACE is not appealing to many older adults as it requires frequent attendance at an adult day care center; nonprofit providers do not have adequate funding to develop new PACE sites or expand existing sites; for–profit providers have not entered into the market; many older adults and their families are unaware of the PACE model; at the state level, Medicaid budget shortfalls have led some states to place enrollment caps at existing PACE sites; and PACE is unaffordable for middle income individuals – enrollees who are not eligible for Medicaid face high out-of-pocket costs (Petigara and Anderson, 2009).

It also appears that states with high rural populations face another hurdle when trying to implement PACE, namely transportation to adult day care facilities. In previous work by the researchers of this study, transportation to adult day services was identified as a barrier in rural Pennsylvania counties (Melnick et al., 2004).

In spite of these limitations, the PACE program, when implemented, has demonstrated that "their enrollees have lower rates of nursing home admissions, shorter hospital stays, lower mortality rates, and better self-reported health compared to non-PACE populations" (Petigara and Anderson, 2009).

Attempts by the researchers to acquire updated assessment information from the state or the literature were not successful. In spite of this, the researchers believe the model should be replicated more often in rural areas, with careful planning to alleviate the barriers identified in the literature.

From this review of the existing literature, it appears that the barriers to successful funding models in the provision of rural HCB care are numerous. However, it is clear that successful funding models must take into consideration the unique characteristics of rural communities as well as their challenges. It is clear that the focus and locus of control must be firmly centered on the rural care recipient. Additionally, the large geographic distances between care providers and the care recipient must be taken into consideration as funding models are developed and approved. What works for urban areas clearly will not work for rural communities as providers must take into account the greater distance between consumers. Finally, innovative programs, such as those offered through PACE, must be made more accessible to rural elders. This may be accomplished through further study of the barriers that impede these elders from using these community-based services.

Pennsylvania State Health Improvement Plan

In response to the federal Healthy People 2010, Pennsylvania developed the State Health Improvement Plan (SHIP) 2006-2010, which is coordinated by the Pennsylvania Department of Health.

The major focus of SHIP is to empower communities to identify, plan for and address local health needs, and to link community-based partnerships with resources (Pennsylvania Department of Health, 2013). At the time of the research, the 2011- 2015 plan was being developed, so updated information was not available.

However, the need for coordination between acute health providers and HCB care providers, as the state moves forward to address the needs of all elderly including those in rural areas, seems to be without question. Indeed, SHIP notes, "Barriers to receiving health care include inability to pay, lack of providers or providers refusal to take certain types of patients, and difficulty in getting to those providers on a regular basis" (Pennsylvania Department of Health, SHIP, 2013). These are the same issues that are repeatedly presented in the literature and what each department of state government will need to address.

Further, specific objectives in the federal Healthy People 2010 were designed to measure access to care, as one objective was to increase the proportion of persons who have a specific source of ongoing care. Therefore, a coordinated state effort to bring acute, intermediate (HCB) and institutionalized care working in harmony to contribute to the well-being of elders needs to be addressed.

At the time of the research, it was not clear if the state had started to work cooperatively at the department level to achieve this coordination. (Note: When the researchers asked about this particular issue, the respondent from the Pennsylvania Department of Health noted that the department was working on SHIP 2011-2015 and therefore no work had yet been done to address that specific objective in Healthy People 2010.

Further, that coordination of care for the elderly or disabled is either addressed by the Department of Aging and/or the Department of Public Welfare. The Department of Health licenses Nursing Homes and Home Health Agencies. It was also noted that coordination is best done at the local level (personal communication, Public Health Program Administrator, Department of Health - Bureau of Health Planning, May 21, 2013).

It is true that the coordination of any individual's care is best handled at the level of service provision. However, a coordinated, constructive effort on the department level to direct the discussion and response, including resources needed at the direct service level, would support a more comprehensive service delivery system. If, as it appears, this coordination is not being done at the highest levels of state government then that is a gap in service delivery that needs to be addressed.

Health Care Reform and The Affordable Health Care Act

Another area that needs to be examined is the Affordable Health Care Act (2010) and its potential impact on the future provision of HCB care services in Pennsylvania. The main components under the act that would impact HCB care centers around Medicaid's 1915(i) Option for Home- and Community-Based Care. According to Families USA (2013), the option became available in 2005 and it allowed states to offer HCB care services under a Medicaid state plan to individuals who were Medicaid-eligible. It limited eligibility to individuals with incomes of up to 150 percent of poverty who would need an institutional level of care if not for the program services.

The changes to 1915(i), which became effective April 1, 2010, make the program meet more of the standard Medicaid requirements for services offered through a state plan. They expand consumer protections, give states more flexibility in some areas, and require that states do more in other areas. (See http://www.familiesusa.org/issues/long-term-services/health-reform/changes-to-medicaids-1915.html).

This provision within the Affordable Health Care act is an important improvement to the current Medicaid HCBS act in that it offers the states flexibility in the expanding the eligibility criteria from 150 percent of the Supplemental Security Income (SSI) to 300 percent. This could provide more individuals with access to services. Additionally, with approval by the Centers for Medicare and Medicaid, states could add additional services not presently covered under this statute and to target specific populations (See http://www.familiesusa.org/issues/long-term-services/health-reform/changes-to-medicaids-1915.html).

At the time of the research, Pennsylvania had not accepted the federal expansion of the Medicaid program. Pennsylvania is not alone in its reluctance to adopt this measure as there is much division across the nation over this expansion (Boehm, E., 2013).

This will be an important area to monitor as it seems that greater flexibility in the state's ability to provide HCB services would assist in providing increased access to more elderly and people with disabilities in Pennsylvania.

Policy Considerations

The researchers offer the following considerations to address the barriers to the delivery of rural home and community-based care alternatives to nursing homes.

Review and expand Life Centers, nationally known as the Program of All-Inclusive Care, or PACE. As this program is a collaborative effort between the federal government and the Pennsylvania Departments of Public Welfare and Aging, it demonstrates collaboration and cooperation in a financially viable and expedient delivery model. Expansion of these services to reach all viable, potential consumers would allow for consolidation and coordination of services for all elders, including those who reside in rural communities.

Establish the Minnesota "Health Care Home" model of care provision. This model appears to not only be a cost effective way to finance services for the elderly and people with disabilities but also puts the locus of control and the focus of the care squarely on the care recipient.

Increase efforts to locate providers in all counties. The researchers are aware of the significant barriers to achieving this goal but it would appear that not having access to a local provider negatively impacts cost and provision of services. In terms of home care services, providers that are located closer to clients might allow for a reduction in amount of time individuals spend on the waiting list for services. Likewise, it would be beneficial to provide community-based services, such as Adult Day Care, that are located nearer to potential consumers who are old, frail, and unable to physically withstand a long commute to and from services.

Increase funding for preventative services that delay institutionalization. According to the data, it appears that consumers must be severely medically impaired to

receive home and/or community-based services. Medicine in general has been moving toward a "preventative" model of care and the need to apply that same philosophy to the elderly and people with disabilities is evident. Preventing and prolonging deterioration seems to be not only more humane but more cost effective. Efforts should be made to study the hypothesis that when funds are redirected toward prevention, premature institutionalization can be avoided.

As expressed on numerous occasions to the researchers by Area Agencies on Aging personnel, the fluidity and lack of secure state funding from year to year leaves much confusion and uncertainty within the system. While state budgets are developed yearly and are subject to ongoing changes, yearly reductions are detrimental to the provision of services overall and particularly in rural areas.

Address barriers to recruiting and retaining staff. Agencies reported several recruitment and retention issues that, if left unresolved, will negatively impact provision of rural home and community-based services.

Consider standardizing records and record keeping. Many providers, both at the public agency level and direct service level, reported difficulties in identifying information requested for this study such as unduplicated persons served and accurate data regarding the provision of services. This makes any analysis of budget and cost effectiveness difficult and does not allow costs to be analyzed. Therefore, it is impossible to say whether services provided to rural elders are cost effective.

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