

# Supporting the Information Needs of Private Paying Consumers

June 2009

Examining the Capacity of Aging Network  
Consumer Information Programs



# Supporting the Information Needs of Private Paying Consumers

## EXAMINING THE CAPACITY OF AGING NETWORK CONSUMER INFORMATION PROGRAMS

Bernice Hutchinson, Senior Policy Advisor

### INTRODUCTION

Private paying consumers need and want information to help them with long term services and support planning for home and community based services. These non-medical, community based services include but are not limited to meals, transportation, and in home support services. They often represent the difference between remaining in communities rather than residing in facilities. Finding information and planning for community based services is not easy, due to fragmented delivery systems, ever-changing benefit programs, and the rapid expansion of products, services, and technologies.

Today's aging network consumer information programs, including information and referral (I&R) and aging and disability resource centers (ADRCs), are evolving to serve a broader continuum of consumers, including disabled and private paying populations. Part of that evolution includes a national culture shift that emphasizes person centered approaches to the consumer experience. As the country focuses on finding solutions to the economic downturn and health reform, aging network consumer information programs represent a cost effective solution to ensuring private paying individuals are prepared to make economical, informed decisions about future long term service and support needs.

This issue brief examines the role of the aging network in supporting the information needs of private paying consumers. It explores the current interest, capacity, and implications for future research and planning for aging network consumer information programs to serve this population.

## A PROFILE OF PRIVATE PAYING CONSUMERS

Private paying consumers represent a large and growing segment of America's aging, disabled, and caregiver populations. The profile of these consumers is complex and multifaceted. It is not a homogeneous group. They have financial resources to devote to community based long term care services and supports. With income levels above the poverty guideline, many are just dollars away from qualifying for Medicaid, but are not eligible for public long term care programs. The group includes a wide range of age cohorts, cultures, ethnicities, and

incomes. Essentially, private paying consumers represent the majority of the U.S. population.

The 2006 U.S. Census data revealed more than 201 million Americans, or two-thirds of the U.S. population, are covered by private pay health insurance.

U.S. Residents by Age	% Above 100% of Poverty Threshold	% Above 200% of Poverty Threshold	% Above 300% of Poverty Threshold
All Ages	87.7%	69.5%	52.0%
Ages 18-64	89.2%	73.8%	57.5%
Age 21-64 with Disability**	74.6%	-	-
Over Age 65	90.6%	64.6%	42.7%
Over Age 65 Living Alone	83.1%	43.2%	24.4%

## WHAT DO PRIVATE PAYING CONSUMERS WANT?

Private paying consumers desire and need streamlined, comprehensive, and reliable information about health care, income security, insurance, housing, financial management, and long term planning. They seek *world class conversations* with highly trained professionals who know the right questions to ask, can provide a range of quality referrals, and provide decision support and options counseling so that consumers make informed choices.

Families with private resources need information and counseling to marshal their resources more wisely. Many want to prevent spending down their resources to qualify for Medicaid community services and institutional living. Others hope to avoid or delay institutionalization. Aging network consumer information programs are uniquely positioned to offer solutions, fill information gaps, and provide counseling that could result in savings to both consumers and government funded programs.

## PRIVATE PAYING CONSUMERS AND THE INFORMATION MAZE

Over the past 20 years, our society has witnessed a dramatic expansion in the scope and diversity of information available to consumers. It is an ever growing market of options that requires consumers to master how to find, collect, process, and discern information from a myriad of sources. Currently, the level of difficulty is heightened because consumers encounter fragmented service delivery systems, ever-changing public and private benefit programs, and the expansion of private sector services. Applications for complimentary services are not integrated or centralized. Information brokers have a range of knowledge and expertise about programs, but while many states have certification requirements in place, there is no national expectation for credentialing. Many federally funded consumer information programs are not tailored to serve private paying consumers because they have historically emphasized serving target populations defined as underserved, low income, and economically disadvantaged.

Another barrier to the individual is that national, state, and local level aging network consumer information programs, like I&R and ADRC, use a number of approaches to branding, so they are not easy to find from state to state and community to community. The continuum of information services offered is not always the same, for example, some offer options counseling while others do not. Quality assurance measures are not uniform across the country. Some of these programs actively market to private paying consumers while others do not. A central question is whether all consumers, regardless of income, can successfully navigate the information maze and ultimately receive a high quality information and counseling experience to make informed decisions about long term services and supports.

## THE CONSUMER INFORMATION PROGRAM EVOLUTION

Since its inception more than 40 years ago, the federally funded aging services network has been a critical provider of essential services and supports for older adults and individuals with disabilities in states and communities across the nation. Connecting to these services and supports has been accomplished through an infrastructure of consumer information programs. Across the nation, information and referral, information and assistance, no wrong door, single point of entry, and aging and disability resource center are the monikers used to identify efforts to provide information, referral, follow-up, advocacy, and options counseling to support consumer choice.

In recent years, the Administration on Aging and Centers for Medicare and Medicaid Services have piloted ADRCs as a new, modernized approach to reaching aged and disabled consumers of all incomes, integrating disparate benefits applications processes, and providing counseling and decision support. This opportunity to build on traditional information and referral approaches requires sufficient funding for all states and uniform approaches to the national ADRC vision so that consumers receive consistent, high quality experiences no matter where they live. This report addresses ADRCs that are funded with AoA grant dollars as well as those that are not. Currently, five states do not have federally funded ADRC programs, while many states seek to expand pilot programs to statewide ADRC coverage. Modernized approaches to consumer information programs require strong, core information and referral components that seek to provide information, referral, follow up and advocacy for a significant element of the consumer calling market. This component can empower independent information seekers and create more opportunities for options counseling and decision support that may require more time and research.

## A WATERSHED PERIOD FOR CULTURE SHIFT

Our nation is in the midst of a culture shift. This culture shift emphasizes person centered approaches to service delivery that place the individual at the center of the experience of finding information, connecting to service opportunities, and receiving supports, no matter where they live. To embrace a person centered approach means to consider irrelevant where a person lives or who is paying for the service. Ensuring that consumers obtain information in a manner they find appealing and acceptable will be a critical marker for the design and development of aging network consumer information programs in the future. Consumers should be engaged in ways they have never been before, with their interests driving the design and end product of consumer information programs that seek to serve them.

In addition to a wide range of incomes, factors such as race, ethnicity, language, gender, education, literacy, and health status that contribute to the picture of diversity in aging, disability, and caregiver populations. These factors shape and frame the unique perspectives each consumer brings to the process of seeking information and services. *World class conversations* recognize a complex mélange of culture and use of technology. These conversations must factor in diverse communication styles, attitudes about conflict, decision making styles, approaches to completing tasks, and ways of knowing that contribute to quality I&R and ADRC experiences. Every stage of the consumer information experience, from simple information requests to options counseling and decision support, must include a diversity framework that is seamless and invisible to the consumer experience.

The baby boomers have arrived with higher income, more education, and greater use of emerging technologies to communicate than their predecessors. They represent a significant portion of the emerging private paying consumer group seeking help with long term planning. With the first baby boomer turning 60 three years ago, there is a unique opportunity to learn from their information gathering patterns and preferences to better inform quality, person centered access to information programs.

In a fast paced, ever changing global information market, consumers connect with information from limitless sources at unprecedented speed. Professional and personal uses of technology continue to grow at exponential rates. Preferred communication paths, including internet, telephone, text, and social networking strategies, are driving new sensibilities and expectations for how fast and frequently we communicate. High value is placed on accuracy and efficiency of time use. Aging network consumer information programs of the future will have to examine current practices and consider new frameworks for delivering the best quality, person centered access to information for all consumers with complex information needs in a complex communication environment.

## AGING NETWORK SURVEY

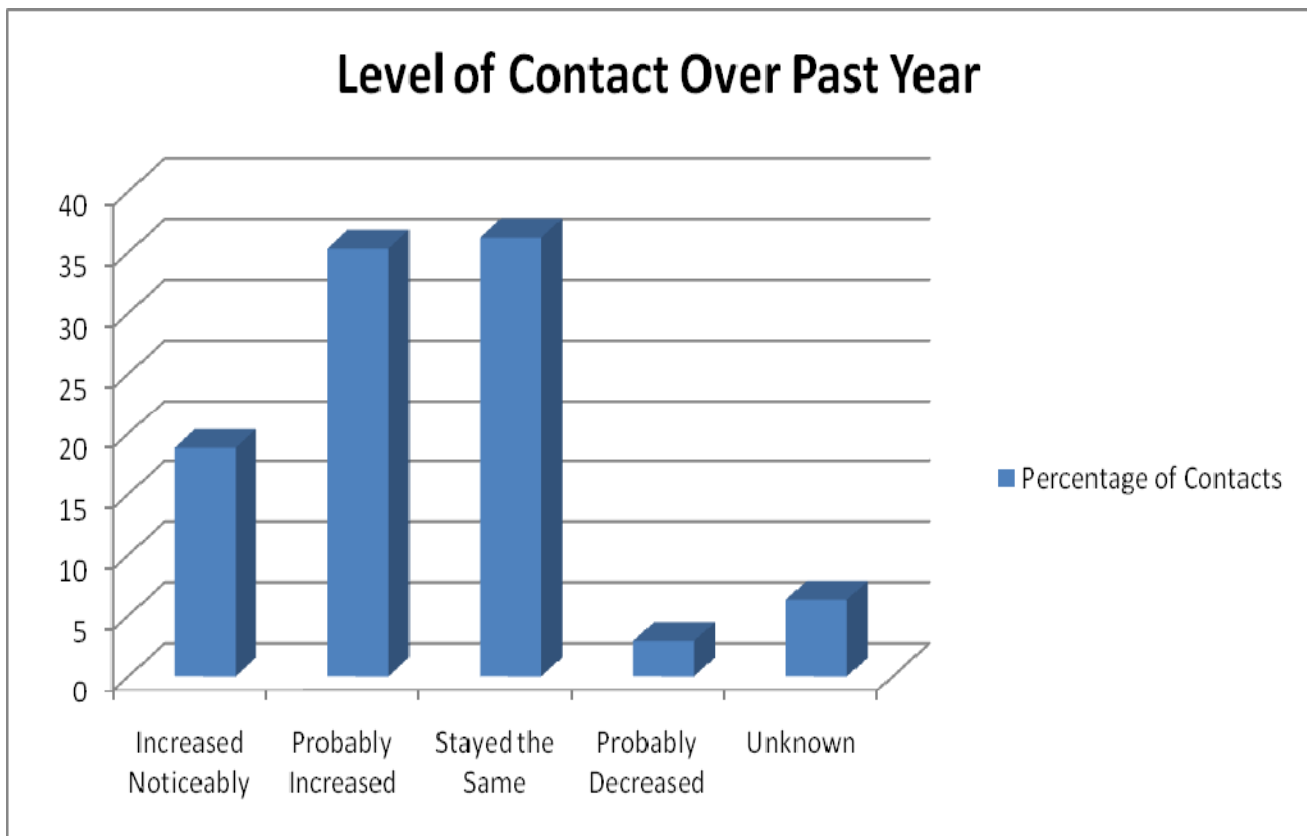
A recent NASUA survey of aging network consumer information programs – including information and referral, information and assistance, single point of entry, and aging and disability resource centers – was conducted to determine interest and current capacity for supporting private pay consumers with long term planning information needs. The 220 individuals that responded to the survey represented state units on aging and area agencies on aging. They also identified themselves as being part of the aging information and referral network and aging and disability resource centers.

A breakdown of the survey respondents:

- 14% -- State Units on Aging
- 58.4% -- Area Agencies on Aging
- 33.9% -- Part of the Aging I&R Network
- 32.1% -- Part of the ADRC Network (with or without federal funding)

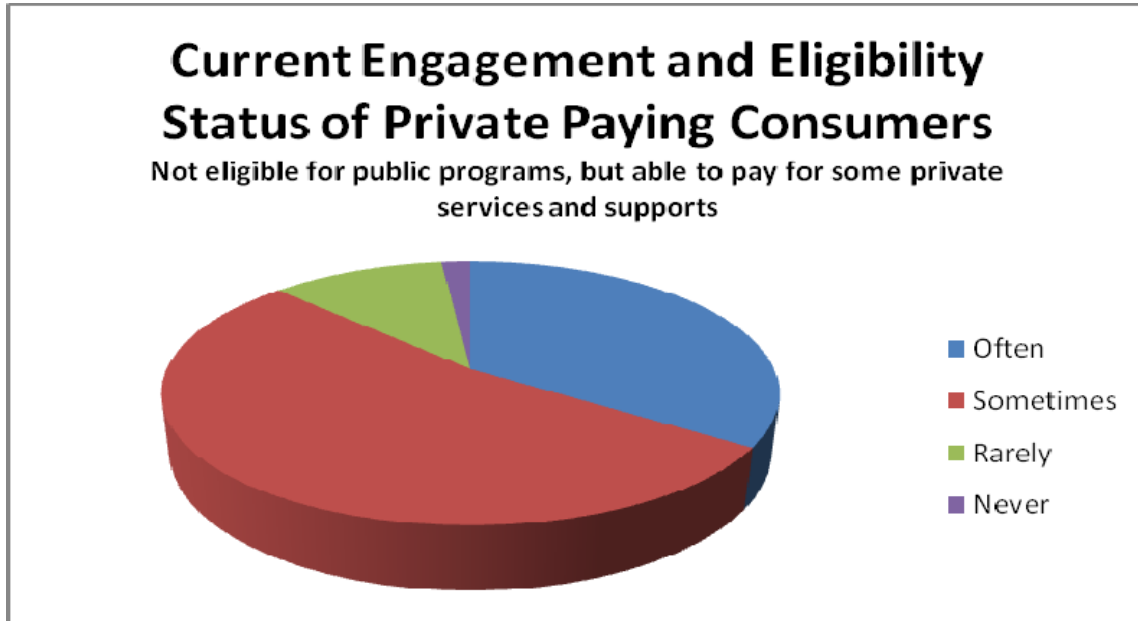
## CURRENT ENGAGEMENT WITH PRIVATE PAYING CONSUMERS

When asked about the level of contact with private paying consumers over the past year, the results were revealing. While 36 percent said the level of contact the organization had with private paying consumers *stayed the same over the last year*, more than one-third indicated the level of contact had *probably increased*. Close to a fifth of respondents thought the contact *increased noticeably*. When the *probably increased* and *stayed the same* categories are combined, the numbers reveal that a significant amount of contact with private paying consumers already exists.



When asked about the specific financial circumstances and eligibility status for public and private benefits, 34 percent of respondents replied they *often* engage with consumers who are not eligible for public programs but are able to pay for some services on a sliding fee or reduced fee basis. Slightly more than half of the

respondents, 52.9 percent, said they were *sometimes* in touch with populations that are not eligible for public programs and are able to pay for some of the services on a sliding fee scale or reduced fee basis. While 10.9 percent of respondents *rarely* engage with consumers not eligible for public programs but were able to pay for some of their services.



## CAPACITY AND INTEREST TO SERVE PRIVATE PAYING CONSUMERS

A series of questions were asked to gauge the organization's internal capacity and interest to serve private pay consumers. Serving the private paying population as a priority ranked below one-fifth for respondents. And less than 10 percent felt that their marketing strategies were attracting these consumers. The numbers show, however, some positive links between serving private paying consumers to the mission and the level of professional staff development.

Organizational readiness and interest:

- Forty-eight percent reported serving private pay consumers was in line with the organization's vision, mission, and philosophy.
- Forty-three percent said staff was willing and comfortable working with the population, having the subject matter expertise, confidence about engaging in discussions, adequate databases and appropriate partnerships in place.
- Twenty-nine percent thought their resource databases include adequate resources for private pay consumers.
- Sixteen percent indicated serving this population is a priority for this organization.
- Seven percent responded that their marketing strategies were effective at attracting private pay consumers.

While private paying consumers are clearly contacting aging network consumer information programs, there is little evidence to show that this as a priority population to serve. Some critical components, like the organizational vision and mission is in line with supporting private paying consumers, and staff willingness and expertise in place for serving the group, suggest a level of readiness. However, more can be done to study this group's interest and capacity to serve private paying consumers.

## MEETING THE INFORMATION NEEDS OF PRIVATE PAYING CONSUMERS

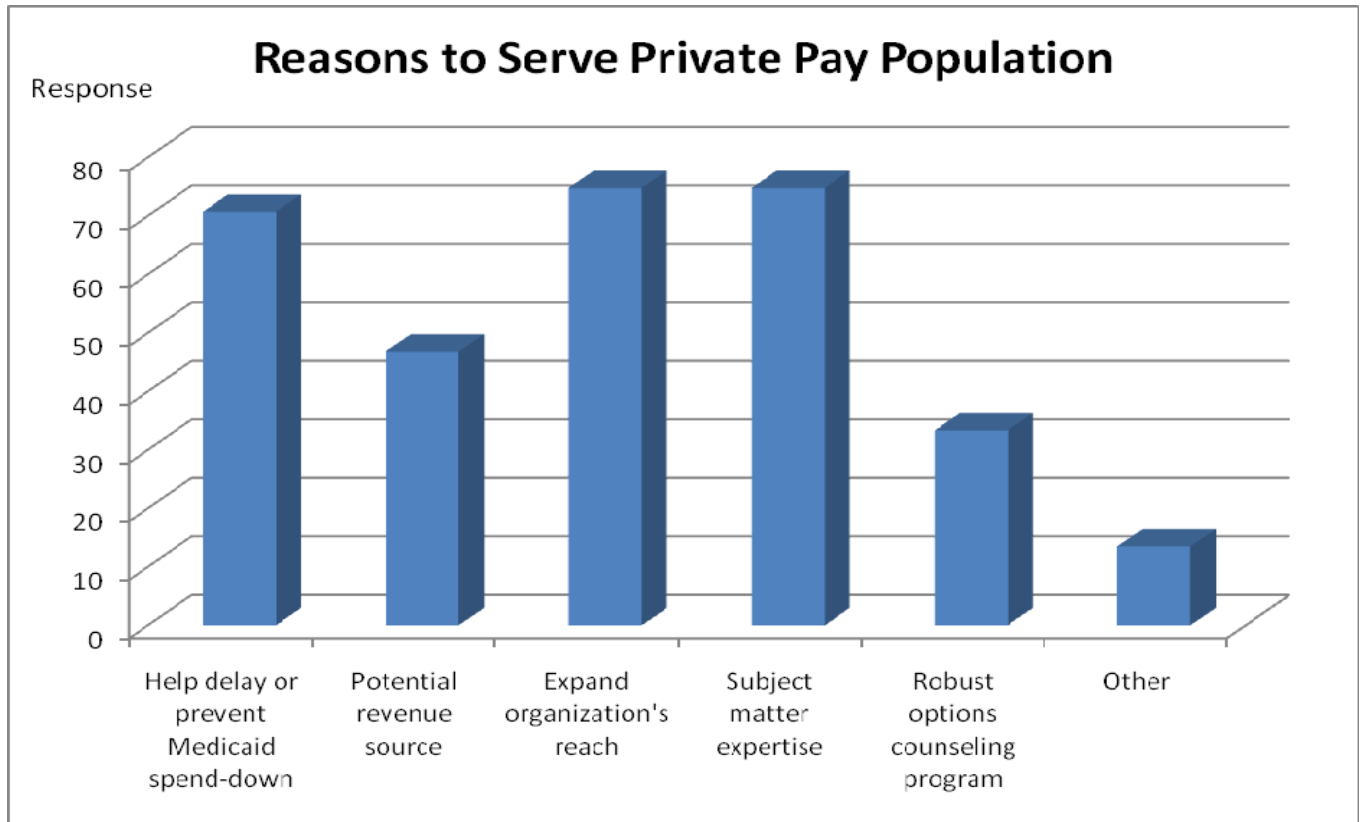
Respondents were asked about the information that private paying consumers typically request when they call. This question requires some analysis of inquirer data, often collected by consumer information programs. When asked *what are the most frequently asked questions of private pay consumers*, the survey respondents provided the following observations:

1. *Cost of Services* – options, service fees and rate scales, opportunity for financial assistance, existing income guidelines and criteria, criteria for spend down.
2. *General Services and Supports* – menu of services, how to locate services, range of options, availability, alternatives for waiting lists.
3. *In-home Supportive Services* – quality assurances, hiring procedures, competency and trustworthiness of home care workers, lists of providers in the community, affordability, and how to locate.
4. *Quality* – service selections available to older adults, the extent to which referrals in the database are based on bonding, and policies and procedures for monitoring and accountability.
5. *Long Term Services and Supports Planning for the Future* – long term care insurance information, guidance with estate planning and estate recovery, reverse mortgages.
6. *Housing* – cost, options, assisted living opportunities, moving and relocation services, financing nursing home placement.

## WHY MARKET TO PRIVATE PAYING CONSUMERS?

A series of questions were asked to determine the interest in expanding current practices or developing new practices serving private paying consumers. When asked what are the reasons the organization should be involved in marketing to and serving private pay populations, an equal percentage of respondents, 74.7 percent, felt that expanding the importance and reach of the organization to a broader base of supporters was just as important as their level of subject matter expertise in long term support options being applicable to this population.

Not far behind was the belief that their organizations have the ability to help people delay or prevent Medicaid spend-down. Almost half, 47 percent, see serving private pay consumers as a potential revenue source. Only one-third of the organizations felt that their options counseling programs were robust. And four percent felt their organizations should not be involved with serving private paying populations at all.



## LESSONS LEARNED ABOUT INTERESTS, NEEDS, AND PREFERENCES

When asked “what have you learned about the private pay population’s interests, needs and preferences for long term care”, the following observations were offered:

1. *Consumers are concerned about savings and affordability of services.* Building consumer knowledge about the cost of services was the most frequently requested service.
2. *Consumers expressed desire to remain at home and independent.* Private paying consumers who currently seek information from the aging network want to know how to achieve this goal through needed supports, opportunities for in home supports and services.
3. *Consumers want variety and choice from their information brokers.* There is great desire for a range of options, comprehensive resources and an opportunity to shop for the best value.
4. *Quality service delivery is also on the minds of private pay consumers.* Not only do they want to remain independent and in their homes, but they define quality through a comprehensive range of service options. Location and proximity of the services was seen as part of the quality equation.
5. *Consumers want to be well informed.* Not only do they want to know where to turn for information, but they expect relative ease with navigating the system. Many of the information providers felt that the

private pay population shared the same interests, needs, and preferences of consumers who are not private paying. Few consumers identified the internet as the preferred vehicle for information.

## TRAINING NEEDS OF CONSUMER INFORMATION PROGRAMS

Preparing to serve private pay populations through aging consumer information programs will require clear vision and goals grounded in professional development. When asked what skills, training, and professional development are needed for information and referral and ADRC providers, the wish list was extensive. The overarching concern was tackling the challenge of keeping abreast of private pay market shifts. State direction through the establishment of policies and guidelines was also identified as important. Information providers expressed a need to capture more perspectives of private pay consumers to anticipate their needs. Database development is critical for serving private pay consumers. There is a need for expanding resources included as well as establishing inclusion/exclusion criteria and policies. Survey respondents also need adequate training on proper database indexing and information retrieval.

Options counselors require more details about providers and their fees. Financial tools to calculate rates on reverse mortgages and long term care insurance were identified as needs. Social work licensure as well as I&R certification will be important credentials to establish credibility as highly trained information brokers and counselors.

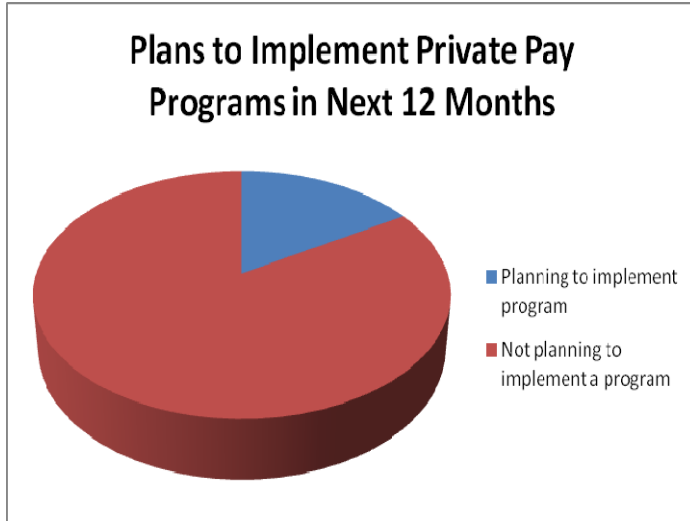
The most notable request for training is to build the knowledge base of information brokers about services beyond the Older Americans Act service package. Respondents need better understanding of the typical pathways for appropriate private pay referrals and details about the services options. Customer service was also identified as a priority training topic. More specifically, customer service was defined as confidence with discussing private pay topics and anticipating consumer needs.

### Top Requests for Skills Building Training:

1. Understanding the functions/service delivery components of information and referral and ADRC.
2. Providing unbiased customer support.
3. Building expertise to serve diverse private pay consumers.
4. Ensuring highly trained, professional standards and ethics for staff.
5. Providing advanced counseling and decision support skills through formal assessment, interviewing, probing, and exploration of alternatives.

Staffing in adequate number by qualified professionals was identified as critical to successful quality information and referral and ADRC efforts to serve private paying consumers. Direct access to existing providers and mechanisms to monitor changing information was considered important for serving a demanding consumer base that values choice and options and minimal difficulties with navigation. Strategies for training included monthly in-service training, partnership development, coalition, task force and committee membership.

## FUTURE PLANS TO IMPLEMENT PRIVATE PAY PROGRAMS



- When asked if organizations plan to develop a fee for service or a cost share program for private paying consumers within the next 12 months, 63.9 percent indicated they have no intentions of doing so.
- Respondents did not distinguish their use of private pay for information programs only, but citing ways their organizations have incorporated private pay into all programs.
- One quarter of responders indicated that they already have a fee for service or cost share program.
- Twelve percent said they plan to develop a new one over the course of the next year.

## OPPORTUNITIES DURING THE ECONOMIC DOWNTURN

The economic downturn continues to find states facing reduced revenues and the challenge of making difficult choices about program cuts in order to stay within their budgets. Programs administered by the State Units on Aging, including those funded by the Older Americans Act, provide a vital lifeline to vulnerable populations – older adults and individuals with disabilities of all ages.

The need for information about aging programs and services has never been greater. A recent report of the National Association of State Units on Aging on the economic downturn reveals that calls to information and referral programs have increased dramatically. With the higher number of inquiries about basic needs for food, clothing and shelter, the aging network finds it is challenged more than ever before to ensure that the most vulnerable have needed information and supports. One question that emerges is whether this is the appropriate time to think about expanding the reach of aging network consumer information programs to serve additional populations, such as private paying consumers. Some would argue that supporting the information needs of private paying consumers is costly and requires significant changes to the program infrastructure, including new technology, program marketing, professional staff development and training. Others would argue that the most challenging economic times provide opportunities for bold, new approaches to cost savings and sustainability.

## SUMMARY

High quality, robust, comprehensive, professional, unbiased, person centered aging network consumer information programs are desired and needed to serve a growing older adult, individuals with disabilities, and caregiver population. But, can these current programs thrive or survive without expanding the scope of the consumer base they serve? More can be done to study states that have already begun to move in this direction.

The recent NASUA survey demonstrates that while not pervasive, a number of aging network consumer information programs are already receiving calls and supporting the information needs of private paying consumers. The experiences begin to create a picture for understanding the preferences for information for private paying consumers. The data also identifies training and technical supports the aging network will need to enhance existing I&R and ADRC efforts to serve private paying consumers.

Seeking opportunities to serve private paying populations may appear, on the surface, to be a costly endeavor because of the cost to ensure the necessary systems framework. When asked if organizations plan to develop a fee for service or a cost share program for private paying consumers within the next 12 months, most indicated that they have no intentions of doing so. However, a cost benefit analysis may reveal that serving private paying populations could prove to generate interest, support, and a revenue base from populations who have resources to pay for services. The end result could achieve long term sustainability for essential consumer information programs like information and referral and ADRC.

## RESOURCES

- Achenbaum, W. Andrew. *The Historical Roles of States in Aging Policy*, *Generations*, vol. 32, no. 3 (Fall 2008): 10-15.
- Collins, James Charles. *Good to Great and the Social Sectors: A Monograph*. New York: HarperBooks, 2007.
- Generations: Journal of the American Society on Aging*, vol. 32, no. 3. San Francisco: Fall 2008.
- Gladwell, Malcolm. *The Tipping Point*, New York: Little, Brown and Company, 2002.
- Kassner, Enid, et al. "A Balancing Act: State Long-Term Care Reform." AARP Public Policy Institute, July 2008.
- Mollica, Robert L., Enid Kassner, Lina Walker, and Ari Houser "Taking the Long View: Investing in Medicaid Home and Community-Based Services Is Cost Effective" *Insight on the Issues*, 126, March 2009.
- Payne, Michael and Applebaum, Robert. "Local Funding of Senior Services: Good Policy or Just Good Politics" *Generations*, vol. 32, no. 3 (Fall 2008): 81-5.
- Polivka, Larry. *The Decisive Role of the States in Aging Policy*, *Generations* vol. 32, no. 3 (Fall 2008): 5-9.
- "Project 2020: Building on the Promise of Home and Community Based Services, a Joint Project of NASUA and N4A." Washington, DC: 2009.
- Schonfield, Lawrence and Hedgecock, Deborah. "State Initiatives to Improve the Access of Older Adults to Behavioral Health Services" *Generations* vol. 32, no. 3 (Fall 2008): 40-6.
- Vision 2010: *Toward a Comprehensive Aging Information Resource System for the 21<sup>st</sup> Century*, National Association of State Units on Aging, Washington, DC.

## ACKNOWLEDGEMENT

This issue brief is a product of the National Aging Information and Referral Support Center and was made possible with funding from the U.S. Administration on Aging. NASUA acknowledges the Lewin Group ADRC Technical Assistance Exchange and the U.S. Administration on Aging staff for their contributions to the NASUA survey design and convening aging network work Private Pay Café focus groups to inform this report.

### For more information:

Bernice Hutchinson  
Senior Policy Advisor  
National Association of State Units on Aging  
1201 15<sup>th</sup> Street, NW  
Suite 350  
Washington, DC 20005  
202-898-2578  
bhutchinson@nasua.org  
[www.nasua.org](http://www.nasua.org)