Executive Summary of Consumer Focus Groups

In April and May 2012, the Pennsylvania Department of Aging hosted focus groups with consumers served by aging services the network. Participants included diverse groups of older individuals, adults with disabilities, and caregivers living in four distinct geographic regions—rural, urban, and suburban—of Pennsylvania. More than 50 individuals participated in the consumer focus groups.

Through guided discussion, participants were encouraged to share their experiences on how—and how well—the network has met their needs and what suggestions they had on improving the scope and delivery of services. To assist them in formulating their responses, participants were asked (prior to the session) to consider the following questions related to each of the four policy themes central to the plan:

Providing the Right Care at the Right Time in the Right Setting

- What plans should individuals make to ensure that their wishes are met for their future care?
- What is the highest priority area related to aging?

Developing Communities in Which to Age and Live Well

- How can Pennsylvania best promote and support aging in place?
- What are the most important issues to address in housing and transportation?

Promoting Health and Well-Being

- What types of prevention support independence and reduce the need to access long-term care services?
- How can we best determine if current programs and services are meeting the health and wellness needs of Pennsylvanians?

Revitalizing and Re-Designing Aging Services

- What are the most effective ways (considering both cost and efficiency) to reach and educate consumers on the programs and services that are available?
- At a minimum, what standard legal services should be offered to older Pennsylvanians as part of the aging service system?

Each of the focus group sessions was recorded and transcribed. This report provides a summary of the combined comments and observations provided by consumers for each of the four themes. Comments and observations are presented as numbered items merely for the convenience of the reader; their order is not intended to suggest prioritization of one item over another. This report also highlights crossover concerns—that is, those that arose in more than one of the four themes and throughout all of the focus group discussions. Within each theme area, these items are indicated with an asterisk; a brief discussion of the crossover concerns is also included in this report.

The results of the focus group provide the Department with valuable information to use in compiling the plan, and, ultimately, in charting its course for the future of the commonwealth's aging services network.

Providing the right care at the right time in the right setting

1) *Ensure that all services and programs recognize individuality and the unique needs of every consumer. Expand programs that support self-determination.
2) *Provide some transitional help when costs or other circumstances make it impossible to stay in one's home, as a bridge between independence and the need for more services.
3) *Ensure that transition of care between hospitals and rehabilitation facilities is seamless. For all transitions, work toward faster access to services.
4) Engage all voices in the conversation about transitioning from Act 150 to the Aging Waiver to ensure that adults with disabilities can expect a seamless transition. Also, maximize the use of all Aging Waiver funding.
5) Examine how Medicare program funding limits access to the right care, at the right time in the right setting.
6) Explore how assisted living can become more affordable for more individuals.
7) *Do more to help those who have worked all of their lives, yet may be ineligible for services and supports. Help those in the middle class.
8) Encourage individuals to save for retirement to lessen dependence on social security and employer retirement plans. However, recognize that the best plans can be destroyed by an accident or health issue, economic downturns, and other circumstances. Help to protect individuals from financial ruin because of these circumstances.
9) *Help individuals commit to a plan for their later years.
10) Encourage individuals to explore long-term care insurance plans.

Developing Communities in Which to Age and Live Well

1) Eliminate burdens such as excessive property and school taxes that make it prohibitive for older individuals to stay in their own homes.
2) Examine how widespread neighborhood degradation and falling property values jeopardize aging in the place of one's choice and explore methods to remedy these situations.
3) *Work for economic development and clean up areas where older individuals live and congregate to ensure safety and accessibility. Encourage economic development that benefits and supports the community, rather than satisfies narrow political agendas.
4) Encourage everyone to work with local law enforcement to proactively improve neighborhoods. Present a united front against crime and blight.
5) *Offer more home modification and maintenance services, perhaps on a sliding scale, that help homeowners remain in their homes. Look at standards in modifications and, where feasible, loosen definitions so that individual needs can be better addressed.
6) Work with utility providers to promote and provide free services, such as energy audits, light bulbs, smoke detectors, and pipe wrapping.
7) *Look for ways to support and expand homemaker service programs.

8) *Examine how greater subsidies or programs can help with home fuel and heating costs. Look at income restrictions and provider limitations associated LIHEAP.

9) Better qualify contractors and establish standards to keep costs down while ensuring quality work. Bond these contractors to provide protection to the state and to the homeowner.

10) *Promote the use and affordability of telehealth, assistive technologies, and other systems that allow individuals to safely age in place. Provide support for the maintenance of these items.

11) *Find ways to ensure greater access to secure, accessible subsidized housing choices throughout the community for older adults and adults with disabilities.

12) *Increase lottery and other public funding to lower transportation costs and to encourage more efficient and convenient transportation route planning.

13) Explore transportation options that incorporate "door-to-door" service and that enable attendants to accompany those for whom they provide assistance.

14) *Increase access to subsidized transportation in rural areas where there is little public transportation and few private providers. Eliminate barriers to crossing county lines for access to needed services. Match transportation capacity with needs.

15) Encourage public transportation providers to better control the hiring and supervision of drivers, as well as provide drivers with sensitivity training on the needs of older adults and adults with disabilities.

16) Work with local communities to offer more activities, including recreational, entertainment, and cultural events, during daylight hours.

17) *Conduct greater outreach regarding the benefits of senior centers. Ensure that senior centers offer a consistent set of services that are ethnically and culturally accommodating. Ask seniors what they want. Use neighborhood-based newsletters or community newspapers to spread the word about senior center programs.

18) *Build or incorporate more senior centers; too many have been closed or consolidated, making it difficult to access programs.

19) Enlist university, college, secondary, and elementary school students to help with outreach to motive older individuals to get out into their communities.

20) Promote the advantages of living in mixed-age communities; even if one must relocate, it can be like living "back in your neighborhood."

Promoting Health and Well-Being

1) *Promote senior centers and their critical role in engaging older adults in socialization, health, wellness, fitness, and financial education.
2) Use community health centers to promote health and wellness programs, including nutrition education and health screening, at senior centers or other venues such as churches and drug stores. In addition, provide incentives for disease screening and early intervention.
3) Recognize the link between isolation and depression and other chronic conditions. Enlist neighborhood volunteers, volunteer coordinators, and block captains to help in communicating where individuals can access health and wellness services and programs.
4) Encourage insurance companies and their agents to do more outreach and coordinate these efforts with existing initiatives.
5) Do more to coordinate with Veterans Administration programs, particularly with prescription drug assistance.
6) Look at examples of health and wellness within the community of adults with disabilities and build on these models.
7) Establish greater access to supportive services for those who care for those with Alzheimer's disease and other forms of dementia. Look at successful support group models and work to emulate those throughout the commonwealth. Work with adult day centers, volunteer ambassadors, and advocates to open the discussion. Create support groups within care communities to share ideas.
8) Explore ways to reach more individuals who may be eligible for home delivered meals.

Revitalizing and Re-Designing Aging Services

1) *Better coordinate services within and among agencies that work with older adults and adults with disabilities. The Department and AAAs should work side by side with Centers for Independent Living and other like organizations in guaranteeing a person-centered approach to services and supports. Work toward amore complete understanding of what it means to live independently.
2) Work with Links to better coordinate services for adults with disabilities and consumers in general.
3) Involve individuals of all ages and differing abilities in designing and administering community-based programs for those served by the aging services network.
4) *Ensure that individuals know what services are available to them and what they are entitled to. Eliminate the confusion and complexity in accessing information. Use various and culturally-appropriate forms of communication and outlets for information, including public service announcements on radio and television, flyers and announcements in libraries, churches, schools, and local stores. Enlist recognizable and trustworthy spokespersons.
5) Develop a comprehensive guideline to the services available by age group.

6) *Do more to provide one-on-one guidance and care navigation on services and supports available. Examine ways to overcome the distrust of certain individuals by stressing this person-centered approach.
7) Make it easier for older adults and those with disabilities to obtain photo identification.
8) *Engage legislators, politicians, and local officials and aging network experts to become involved in talking about programs and services to groups of individuals at senior centers and other venues where older adults and adults with disabilities gather.
9) *Work to overcome the attitude among some individuals that they are "too young" or "too proud" to consider services. At the same time, provide information a bit at a time so that they can retain what they have heard.
10) *Do not cut funding to services that support older adults and adults with disabilities. Seek innovative solutions (e.g., partnerships, volunteers) to help ensure that essential, person-centered services continue. Where cuts are necessary, provide adequate notice and assistance in pursing alternatives.

Crossover Concerns

Providing clear communication about programs and services

Although the aging services network provides an array of services and supports, many individuals are unaware of the programs that may be available to them. Participants urged the Department of Aging and its partners to more effectively communicate these services and supports. This includes not only employing traditional means of communication but also exploring innovative approaches to reach older adults and those with disabilities in the places where they congregate and via mechanisms they trust and understand. Further, work to overcome barriers set up by individuals who may be in need of services but are reluctant to discuss these needs.

Ensuring a person-centered approach

The Department of Aging must engender greater cooperation and coordination of services within and among agencies and other partners that serve older adults and adults with disabilities. Participants urged the Department to include its consumers in the conversation and in implementing programs. In doing so, the Department can not only expect greater streamlining in the delivery of service, but, more importantly, help to ensure that all services and programs take into account the unique needs of every individual in a true person-centered approach.

Smoothing the path for transition of care

Many spoke of the need to ensure a more seamless path when individuals transition from one setting to another. This includes transition through the entire continuum of care, be it from hospital to rehabilitation center or from moving from one's home into another residence. Intrinsic to this seamless path is faster access to the appropriate services through care navigators, who can guide individuals through the maze of available programs.

Facilitating aging in place

Participants spoke of their desire to stay in their homes as long as possible. In order to do so, many noted the need for greater assistance in home maintenance and modification, even for the near poor and middle class individuals who may be outside of current income limitations for these programs. These services include simple assistance, such as help with heating and fuel costs and light housekeeping, to more complex renovations, including bathroom modification and room widening. Many stated that the commonwealth should also consider greater implementation of telehealth and other assistive technologies that facilitate aging in place.

Participants also stressed the need to encourage economic development and municipal policies that benefit and support safe communities in which to age. This includes greater choice in secure, accessible subsidized housing options throughout the community.

Also key to aging in place is affordable and accessible transportation, particularly in rural areas. Further, regardless of where participants call home, there is a need to better coordinate routing and scheduling to provide more convenient transportation.

Strengthening the vital role of senior centers

Participants throughout the state spoke of the vital role of senior centers in enriching the lives of older adults. They urged continued funding for the numerous recreational, educational, and health and wellness activities that these hubs provide, as well as assistance in creating relevant programming for a culturally and ethnically diverse population of older adults. Additionally, participants stressed the need for a greater number of senior centers; many sites have closed their doors, creating a vacuum in certain communities.

Promoting individual responsibility

Lastly, participants in all of the focus groups emphasized their motivation, desire, and ability to care for themselves in all aspects of their lives. However, they also recognized that circumstances beyond their control may impact their ability to do so. While stressing the need for individual responsibility, they urged the Department to continue to work as an advocate and steward, and to seek innovative ways to fund programs and services so that the funding will continue to be there to support those in need.