

Appendix H: Summary of Subject Matter Expert Focus Groups

Executive Summary of Focus Group Sessions

Introduction

In February and March 2012, the Pennsylvania Department of Aging (PDA) hosted a series of facilitated focus group sessions in each of the five Pennsylvania Council on Aging regions. The purpose of these sessions was to engage subject matter experts in exploring identified opportunities and challenges related to the Commonwealth's aging and disabled citizens. The feedback from these focus group sessions (as well as the information-gathered at other stakeholder forums) will be used by PDA in developing the four-year State Plan on Aging, as mandated by the United States Department of Health and Human Service's Administration on Aging.

At each of the five sites, individual focus group sessions addressed one of the four PDA State Plan policy themes:

- Providing the right care at the right time in the right setting at the right intensity and duration
- Communities in which to age and live well
- Promoting health and well being
- Revitalize and re-architect aging services

To help frame the overall discussion, participants were asked to consider the following factors (as applicable) as the related to their theme:

- The role if innovation in addressing opportunities (including entrepreneurial investment and public-private partnerships)
- The unique needs of the under-60 disability community
- The contrasting needs of rural and urban communities
- The effect of diversity on addressing needs (cultural, linguistic, orientation, etc.)
- Means of bringing the "best of Pennsylvania to Pennsylvanians" from our academic, research, and private institutions
- Regulatory or policy barriers to be addressed to better provide services
- Promoting consumer choice and control
- Accomplishing outcomes while spending money more efficiently and effectively

Each of the focus group sessions was 90 minutes in duration. In total, 125 subject matter experts, in the fields of academics, advocacy, business, community planning, healthcare, elder law, private and public foundations, government, insurers, long-term care, public health, and transportation, participated in the focus group process.

Each of the focus group sessions was recorded and transcribed. This report provides a summary of the combined comments and observations provided by the subject matter experts in the five focus groups for each of the four themes. The report presents the issues elemental to the theme, specific barriers/challenges related to the issues, and opportunities and/or solutions toward addressing the issues. It also includes the "systemic" or cross-cutting findings across all four theme areas.

The issues, barriers/challenges, and opportunities and/or solutions from the focus group session are presented as numbered items merely for the convenience of the reader; their order is not intended to suggest prioritization of one item over the other.

Focus Group Theme: Providing the Right Care at the Right Time in the Right Setting at the Right Intensity and Duration

Issues

- 1) How do we ensure a person-centered system, one that truly addresses the needs and choices of the individual?
- 2) How do we coordinate transition of care to ensure that individuals do not regress because the necessary HCBS supports are not there?
- 3) How do we ensure appropriate access to the right care and eliminate excessive care?
- 4) How does we ensure system capacity to promote flexibility in light of diversity and demographics?
- 5) How do we communicate with individuals and their families in a comprehensible way?
- 6) How can we ensure consistent and cohesive communicate between facilities and HCBS providers?
- 7) How do we provide services and supports to a greater number of individuals?
- 8) How do we encourage individuals and their families to take more responsibility for their future needs?
- 9) How do we better advocate for the elderly and disabled, particularly in protecting their legal rights?

Barriers/Challenges

- 1) Regulatory requirements stand in the way of local autonomy in providing access to necessary programs and services and create hurdles for providers.
- 2) Regulatory requirements can actually penalize individuals in need through inconsistent and inefficient controls and misguided authority. These obstacles may be forcing people into nursing homes.
- 3) The current network is fragmented, with duplication of services and lack of information sharing (including consistent provider-to-provider medical information sharing).
- 4) There is inconsistency in waivers administration from county-to-county (e.g., notification, compensation, follow-up).
- 5) Providers (physicians, other healthcare providers) are not well informed about issues related to the geriatric population. Further, access to qualified providers is limited.
- 6) Individuals seek help or enter the system too late.
- 7) A “one size fits all” approach does not consider the varying perspectives of those in the network (younger vs. older seniors, younger disabled vs. older disabled, diagnosis vs. functional ability). There is conflict between independence vs care philosophies.
- 8) There is a lack of information regarding support programs for caregivers.
- 9) There is a general need for more HCBS workers.
- 10) Individuals may not be well informed about end of life issues. Further, healthcare providers are hesitant to broach these issues and may not be clear on their patients’ wishes.

- 11) Transportation is a major barrier to accessing programs and services, particularly in rural areas. In addition, many transportation systems cannot accommodate individuals with certain physical barriers, including those who are hearing and vision impaired.
- 12) There is a lack of accessible, available, and affordable housing in safe communities.
- 13) Massive resources are spent on end-of-life care that does not necessarily improve the patient's quality of life.

Opportunities and/or Solutions

- 1) Review programs and services requirements that limit local flexibility. Streamline processes so that individuals can access services more quickly. Create an interdisciplinary team that looks at how programs can be merged or eliminated.
- 2) Expand matching funds programs between the state and families to potentially eliminate waste and increase the level of support for HCBS. Look at cost sharing for those who can afford it.
- 3) Explore innovative federal programs, such as those conducted by CMS, as models for delivery of programs and services.
- 4) Use PACE as a model for services across the board.
- 5) Examine how a mix of private/public funding can enhance flexibility and fund a greater range programs and services through various providers.
- 6) Provide navigators to streamline care transitions. Involve providers at all levels to coordinate the appropriate level of care.
- 7) Integrate access and reporting systems to eliminate redundancy (e.g., 211 and LINKS).
- 8) Ensure consistency among counties in waiver programs administration. Facilitate greater communication between hospitals and the department, particularly for individuals on waivers. Structure waiver programs so that they do not force individuals into undesirable living situations just to capture the funding support. Look at the potential for personal care homes vs. institutional care. Look at how risk aversion may play a prohibitive role in tapping into these resources.
- 9) Consider a mix of HCBS and institutional services for certain individuals (e.g., intensity of therapy at the right location).
- 10) Promote physician education on geriatric issues, perhaps with some incentives. Involve the Pennsylvania Medical Society and medical schools to raise awareness.
- 11) Establish licensing criteria for geriatric credentialing for care managers and social workers. Encourage inter-professional training approaches through the domains of the aging and disability communities. Seek out transformational leaders in the field of aging who can step up with great ideas.
- 12) Identify someone in each county as a geriatric expert (geriatrician) that can start outpatient assessment centers (particularly for assessing dementia). Supplement Medicare funding in the development of these centers.
- 13) Stress early intervention and do more to promote AAAs as the entry point. Educate individuals, their families, and the public not to fear the future, but to act before crisis strikes. This is especially pertinent in caring for the Alzheimer's patient, where intervention should begin at the point of diagnosis.
- 14) Offer some form of long-term care savings that would change an individual's entry point into system.

- 15) Look at areas within HCBS where more informal caregiver—but competent and Act 134 cleared—support (outside of the family) can be made available. Consider not only efficiency but cost (costs to providers of care vs reimbursement). Realize the intrinsic link between workforce development and HCBS. Work in partnership with organizations that train and hire workers to ensure not only competency but also a livable wage.
- 16) Explore the greater use of technology in the home.
- 17) Provide hearing aids to all Pennsylvanians.
- 18) Enhance senior center programming to address the diverse desires and needs of seniors. Encourage attendance, self-sufficiency, and ownership of the senior center by seniors. Offer small financial or non-monetary incentives to get programs off the ground.
- 19) Encourage partnerships. Begin at the state level to encourage cooperation and information sharing among departments and agencies. Work with counties on sharing information. Build on natural collaboration models already in place.
- 20) Develop and enhance volunteer engagement programs, especially peer-to-peer volunteers.
- 21) Create the means to share and disseminate best practices that are in use throughout the state. Incorporate the use of technology (e.g., Webinars, virtual tours). Tap into the world of non-profit and for-profit providers for best practices, as well.
- 22) Communicate what services are available and how to access them through both conventional (e.g., publication, media) and non-conventional means (e.g., information dissemination at bars, barbershops, casinos, and libraries, information prescriptions, electronic newsletters). Set up a speaker's bureau for direct communication between the state and various organizations throughout the state.
- 23) Engage foundations in Pennsylvania to join the discussion on how to do things differently with their philanthropic dollars. These funds can take on more risks than public dollars.
- 24) Look for partners that might be "out of the box." For example, partner with mortgage bankers to develop accessible housing and for financing home improvements that promote visitability.
- 25) Partner with the Department of Education to share transportation mechanisms and school facilities (particularly in rural areas) to create accessible programs for seniors (e.g. computer classes taught by students). Encourage community outreach to help support these programs. Partner with colleges, universities, and community organizations to open their facilities and resources to older individuals and those with disabilities.
- 26) Do more to educate individuals on end of life issues (including powers of attorney and living wills) and how to ensure that their wishes are met.
- 27) Encourage the use of the POLST (Physicians' Orders for Life-Sustaining Treatment) form or similar model among physicians, healthcare providers, and individuals. Involve the Department of Health in this initiative. Explore how the APPRISE model might serve as a vehicle for POLST or other models. Reach out to community volunteers to assist AAA staff.
- 28) Encourage healthcare providers to examine evidence-based research on the risks vs. benefits of end of life care. PDA could help with providing guidelines or education for providers.
- 29) Enhance the level of support for adult day care for the benefit of individuals with dementia and their caregivers.
- 30) Delve deeper into advocacy issues related to the rights of older individuals and the disabled and projects that address them. Do more to promote the Ombudsman program.
- 31) Partner with law enforcement and the courts to better address fraud and abuse. Educate law enforcement and the courts on aging protective services programs and other services. Work to eliminate ageism, enhance awareness of the rights of older individuals, and slow the rush to guardianship.

- 32) Provide incentives to local governments to cross-coordinate programs. For example, provide incentives (e.g., planning grants, technical assistance) to counties to help achieve the goals of the four-year plan.
- 33) Sanction demonstration projects (including those conducted by Pennsylvania's universities).
- 34) Break down barriers to fundraising by public entities.

Focus Group Theme: Communities in Which to Age and Live Well

Issues

- 1) How can we enable individuals (who wish to) to stay in their homes?
- 2) How do we encourage independence and access to programs and services through transportation and housing?
- 3) How do we communicate what programs and services are available?
- 4) How do we ensure that older adults have access to appropriate medical care?
- 5) How can we provide sustainable funding for staff and operations?

Barriers/Challenges

- 1) It is difficult to reach individuals before they are in crisis mode and educate them on their options.
- 2) Pennsylvania offers a limited amount safe, affordable, accessible, and appropriate housing stock, particularly in urban areas
- 3) Many homes require cost-prohibitive modifications and maintenance (both general upkeep and deferred maintenance), making it difficult for people to stay in their homes.
- 4) There are inconsistencies in technological infrastructure that prohibits certain HCBS services.
- 5) Zoning restrictions, inconsistencies between communities, regulations, residential vs. commercial (licensed vs. institution) codes make it a challenge to age in place.
- 6) There is a lack of cooperation between state agencies and local housing authorities.
- 7) The limitations on who can live in PHFA housing are restrictive, particularly for younger individuals with disabilities.
- 8) Funding cuts in public transportation have had an impact on accessibility to services in urban and suburban areas.
- 9) There is a general lack of available, accessible, and convenient transportation that links individuals to services. This is especially a concern in rural areas.
- 10) A lack of geriatric and mental health professionals limits access for patients.
- 11) It takes an inordinate amount time it takes to get supports in place to enable transition of care from an institution to HCBS.
- 12) Hospital discharge policies tend to "direct" people away from their home
- 13) MA income level limitations differ between nursing facilities and one's own home, limiting choice due to financial considerations.

- 14) There is a lack of support for individuals whose income is just over the regulatory limit (and the middle class in general). This limits individual choice because assistance with certain services is out of reach, yet many individuals cannot afford the out-of-pocket expense.
- 15) Awareness on community supports and how to access those supports is lacking.
- 16) Regulatory barriers limit HCBS services.
- 17) Systems do not do enough to address cognitive, hearing, and linguistic barriers.

Opportunities and/or Solutions

- 1) Partner with organizations such as AARP for planning and education initiatives. Use private sectors as advocates for shared priorities.
- 2) Encourage community level involvement for housing, transportation, and supportive services from the business community. Facilitate community-based comprehensive discussion, planning, and integration of resources.
- 3) Seek mechanisms for private support of aging initiatives (e.g., contributions on electric bills, AARP volunteers, peer connect programs). Incentivize private donations (perhaps through tax breaks) to support the NORC.
- 4) Explore best practices for shared living (e.g., DOM care, live-in caregivers, informal communal housing).
- 5) Connect housing stock to individuals who may be able to purchase these homes from older people. Look at models throughout the United States for guidance.
- 6) Offer incentives for home modifications to allow people to remain in their homes, such as assistive technology, stair lifts, and ramps. Promote the benefits of telehealth and other technology (including infrastructure). Provide funding for “chore services” for home safety modifications and other inexpensive supports.
- 7) Help to develop public/private partnership to encourage landlords to purchase homes and make them accessible.
- 8) Mandate that housing agencies work with aging agencies on the local level.
- 9) Promote multi-generational communities where individuals of all ages support one another and where volunteer efforts drive community building. Encourage agencies to partner with local schools to engender intergenerational support opportunities. Develop guidelines for communities to make the right planning decisions to help citizens age in place. Encourage realistic economic development at the local level.
- 10) Look at state and fed regulations that make it difficult for municipalities (especially rural towns) to make infrastructure improvements that support a community in which to age in place.
- 11) Educate public officials in transportation planning that considers the longer-term outcomes. Provide incentives for this type of planning. Explore models for best practices in transportation (e.g., “walking cities,” volunteer and other informal transportation networks, doorstep to bus stop, door to door).
- 12) Enlist insurance agencies to help with transportation issues, in setting up networks for those who can no longer safely drive. Use occupational therapists to set up car modifications to help ensure driver and passenger safety.
- 13) Work to erase the stigma associated with public transportation. Make public transportation more accessible to individuals who are hearing or vision impaired. Partner with private organizations to assist this effort.

- 14) Expand ACCESS services related to transportation. Expand lottery funding to pay for transportation for younger seniors and look at co-pays. Explore greater flexibility in SharedRide (e.g., fixed routes versus no fixed route), on a county-by-county basis. Investigate the feasibility of volunteers drivers, home health care drivers, or other inexpensive means to supplement SharedRide programs.
- 15) Eliminate regulatory/insurance barriers and examine mechanism to purchase mini-vans for community volunteers to use (especially for long-distance trips). Promote flexible shared transportation systems (e.g., Zip Car rentals, contracting with nursing homes for shared transportation). Tailor transportation funding to the unique needs of each region (e.g., non-accessible mini-vans that can travel on rural roads).
- 16) Look at models in rural Pennsylvania, where there are many examples of cooperation and collaboration in helping others in transportation and housing.
- 17) Educate family caregivers on the supports available to them.
- 18) Promote personal responsibility and planning, including looking at their homes for accessibility in the future.
- 19) Help older individuals and those with disabilities to self-advocate with their healthcare providers. Empower them with education on their disability and what they need. Geriatric case managers can assist with this. CILs can play a role in this educational effort. Advocate for more education on end-of-life care and chronic condition management (including brain injury).
- 20) Make access to information easier with myriad channels of communication that consider the cultural, linguistic, educational, and generational differences among individuals.
- 21) Promote educational outreach to healthcare providers on aging programs and services. Partner with the American Geriatric Society (Pennsylvania chapter), the Pennsylvania Medical Society, and the Pennsylvania Medical Directors Association. Encourage these partners to also promote specialized medical/healthcare education in all facets of geriatrics (including behavioral health) to help address the gap in specialty providers.
- 22) Encourage information sharing among all service providers. Use ARDCs as a central point of contact for information regarding aging and disability network services. Conduct asset based planning to get an inventory of what services are available in a community to eliminate redundant services.
- 23) Incentivize mental health/behavioral partnership with aging at the local level. Link with HCBS. Further develop existing funding to enable this link. Include home drug and alcohol screening in HCBS.
- 24) Look at state requirements for those on SSI; eliminate barriers that hinder these individuals from qualifying for Assisted Living facilities. Explore public/private partnerships to make Assisted Living more accessible.
- 25) Eliminate waiver requirements for personal care homes.
- 26) Streamline systems for transition of care. Educate hospital discharge personnel on HCBS services and discourage practices that “direct” individuals away from their homes. Expand Community Choice.
- 27) Champion the critical role of senior centers in identifying those in crisis and supporting innovative programming. Yet, look at improvements to senior center programming (e.g., telehealth units, use of their kitchens to support nutrition programs) that are both cost-effective and support HCBS.
- 28) Offer a funding source that the middle class could access (perhaps on a sliding scale).

Focus Group Theme: Promoting Health and Well Being

Issues

- 1) How do we promote health and well being (including both physical and mental health) in light of an individual's unique circumstances?
- 2) How do we encourage individuals to develop and strengthen their own capacity, as well as the informal supports (advocacy, family, and education) necessary for their health and well being?
- 3) How do we develop the infrastructure necessary to support those with chronic conditions, including Alzheimer's disease?
- 4) How do we ensure that care transitions are managed in a way that supports the desires and needs of the individual?

Barriers/Challenges

- 1) Individuals are not always prepared to accept personal responsibility for their health and well being.
- 2) Regulatory issues, funding streams, and institutional policies inhibit transition of care.
- 3) Individuals fear facing chronic care diagnoses, such as dementia.
- 4) There are instances of misdiagnosis and under treatment of chronic conditions.
- 5) There is a need to increase home care provider infrastructure.
- 6) Rehab hospitals are incentivized to get patient home vs. into skilled nursing units, which can lead to hospital re-admissions.
- 7) The reams of data that come in from these systems carry the potential for increasing physician liability.
- 8) There are very few adult day centers for Alzheimer's patients.
- 9) Regulatory barriers limit home the delivery of HCBS.
- 10) There are inherent difficulties in translating evidence-based research into policy and program development.
- 11) Middle income individuals are often unable to assistance programs, due to financial limitations.

Opportunities and/or Solutions

- 1) Support a holistic understanding that an individual's health and wellbeing is influenced by their unique circumstances, including living arrangements, income restrictions, social supports, and family situation.
- 2) Encourage individuals to develop and strengthen informal supports for their own health and wellbeing. Emphasize advocacy, family supports, and education as critical components of informal supports. Reach out to people earlier, along the way throughout adulthood. Support preventive approaches (e.g., health screenings at public events); secondary approaches (once a problem is identified, get them the help); and tertiary approaches that emphasize maintaining quality of life.
- 3) Develop educational initiatives that reinforce the behavioral changes necessary to adopt healthier lifestyles, then provide the supports such as workshops to show that they are putting these notions into practice (pre- and post-assessments).

- 4) Partner with mental health professionals and agencies, recognizing that mental health is as important as physical health.
- 5) Explore and emphasize evidence-based programs designed to support healthy aging and health and wellness education. Develop a menu of affordable “shovel ready” evidence-based models tailored to older adults. Use the ready resources from research and programs developed by state universities, such as the University of Pennsylvania and the University of Pittsburgh. Introduce state and federal legislators to the innovative health and wellness programs underway throughout the state, as a means of raising awareness and channeling greater funding.
- 6) Institutionalize flexibility in terms of service delivery and approaches to health maintenance. Encourage payers (both public and private) and healthcare systems to assist in incorporating this flexibility.
- 7) Encourage the development of dynamic senior centers as centers as hubs for socialization and education. Make them attractive to baby boomers with diverse programming (e.g., fitness programs at private gyms, yoga, nutritional education). Use train-the-trainer model (as in Silver Sneakers). Provide telehealth monitoring at the center. Offer incentives to pull people into senior center programming.
- 8) Link senior center programming with those of rural cooperative extension offices (as these sites are a hub of activity for seniors in rural areas). Look at existing programs for healthy older adults (e.g., AARP good driver program, Misericordia open track, Weight Watchers programs for older people, free or reduced cost clinics). Partner with the program directors to raise awareness of these programs that encourage self-management. Engage schools and other public entities to share their facilities for fitness and education programs.
- 9) Tap into volunteer networks (e.g., community time banks, RSVP, speaker’s bureaus). Further, explore models that offer peer-to-peer education (preferably with volunteers who have some health care background).
- 10) Encourage programs that provide nurse- or dietician-led education on health and well being. Look at models on nutrition education and choice throughout the state (e.g., flyers in delivered meals for the home-bound, “smart dining” restaurant meal program coordinated by senior centers, later-day meals, “super supper” supper clubs” with speakers and fund raising, cost-sharing for home and congregate meals.)
- 11) Connect with seniors in the settings where they gather (fast food chains and other restaurants, funeral homes, barbershops, banks, credit unions, physician’s offices), but be sensitive to cultural and regional barriers. Tailor the message to different audiences.
- 12) Implement a searchable, easy to use means for individuals to learn about the wide array of services Pennsylvania has to offer. Better publicize the 211 system and LINKS.
- 13) Introduce care navigators to ensure close follow-up with primary care physicians, nurse practitioners, and physician’s assistants, as well as to ensure medication monitoring after an individual is discharge from hospital to home. Use existing supports (e.g., AAAs) to develop these positions.
- 14) Adapt existing pre-admission evaluation (completed by a multidisciplinary team) to make expeditious decisions on transition of care. Assist healthcare providers in developing a comprehensive geriatric assessment.
- 15) Coordinate state-funded services for transition of care with those offered by private insurers, such as the concierge model for follow-up monitoring.

- 16) Prepare and disseminate appropriately written materials to patients and their caregivers so they better understand their chronic conditions, how to manage the conditions, and their choices. Help AAAS develop a quick reference sheet for patients as they are discharged from the hospital regarding the programs and services relevant to their chronic condition.
- 17) Promote the role of social worker in physician's office for screening and identifying those at risk for chronic conditions.
- 18) Encourage flexibility in the payment for palliative care. Preventative approaches should be emphasized as well, with a focus on costly and common conditions related to heart disease, cancer, and arthritis. This flexibility and these approaches should include caregivers, families, and informal support systems.
- 19) Prioritize funding to offer more comprehensive supports for those with Alzheimer's and for respite for caregiver at home. Look at easing Medicare requirements that prohibit an Alzheimer's patient's admission to a nursing facility unless they've spent 72 hours in the hospital. Flexibility in this requirement would ease the burden of Alzheimer's families in getting individuals placed.
- 20) Set up a health surveillance system to capture data on risk factors for Alzheimer's and other chronic conditions. Link into federal level initiatives related to Alzheimer's research and management (e.g., National Alzheimer's Plan), as well as initiatives conducted by Alzheimer's associations in Pennsylvania and other states.
- 21) Examine licensure requirements and reimbursement rates for adult day care to allow specialized care based on patient's needs.
- 22) Encourage discussion among healthcare providers and patients on pain management and end-of-life care considerations (including living wills, powers of attorney, and guardianship).
- 23) Expand the use of assistive technology (e.g., telehealth systems) in the individual's home to capitalize on virtual health for diagnostic and monitoring. Examine how to break down barriers to the more wide spread use of these systems (e.g., multi-state licensing, reimbursement). Use technology to increase accessibility to and coordination of care (e.g., to enable a case worker to be virtually available in numerous medical offices, electronic health record)
- 24) Research the feasibility of home-visiting health coaches, based on the visiting nurse model. Encourage informal supports. Use trained HCBS caregivers and volunteers (e.g. Meals on Wheels volunteers) as the "eyes and ears" on the in-home client.
- 25) Expand LIFE programs as the model of care for keeping people out nursing homes. Explore the feasibility of similar programs for younger people.
- 26) Work with healthcare associations to better educate physicians and other healthcare professionals on geriatric issues. Tap into private providers that offer area health education. Work with them on their existing programs for outreach to healthcare professions (e.g., physicians, geriatricians, physical and occupational therapists, ophthalmologists and opticians) on the local level.
- 27) Consider geriatric certification for case managers. Seek private support to help fund education and implementation.
- 28) Coordinate providers who provide HCBS (including AAAs, LINKS, and private agencies) to eliminate duplication of services. Strengthen existing health information exchanges. Use these agencies to disseminate information.
- 29) Explore and disseminate information to providers on newer models for coordination of services, such as the Medical Home Model, the geriatric emergency room, and care transition advocates in hospitals.

- 30) Encourage long-term care institutions to offer a wider range of self-contained services (e.g., dental care).
- 31) Create benchmarks to determine if current programs and services are meeting the health and wellness needs of Pennsylvanians. These could include emergency room use, re-hospitalizations, nursing home admissions, membership/enrollment in senior centers)
- 32) Facilitate links or enhance existing partnerships and collaboration between local and county governments and agencies. Push local governments to convene stakeholders to conduct community assessments to determine what citizens want.
- 33) Encourage conversations regarding estate recovery (in a positive way). Help older individuals and their families better understand what this means in terms of family assets. Create a paralegal program to help oversee the assets of older individuals and help them to determine if they can stay at home. Involve AAAs in home visitations to introduce asset evaluation.
- 34) Make it easier for individuals to make inexpensive home modifications (e.g., grab bars, double railing).
- 35) Work to ensure access to vibrant, affordable housing and access to care via sustainable transportation systems.

Focus Group Theme: Revitalize and Re-Architect Aging Services

Issues

- 1) What are the most effective ways (considering both cost and efficiency) to reach and educate consumers on the programs and services that are available?
- 2) In an environment of economic constraints, what should the respective roles of PDA, the commonwealth, and other members of the network be in addressing long-term services and supports?
- 3) What are some ways to enhance how the aging network delivers protective services?
- 4) At a minimum, what standard legal services should be offered to older Pennsylvanians as part of the aging service system?
- 5) How can existing services be enhanced or new ones developed to address the growing needs of today's older individuals experiencing behavioral health issues, drug and alcohol abuse, and homelessness?

Barriers/Challenges

- 1) Silos exist between different human services realms, hindering coordination of services.
- 2) There is a lot of "noise" out there, with different agencies trying to track individuals within the aging network.
- 3) Seniors do not know what is out there for them. Current communication of programs and services is not as effective as it might be, due to geographic, cultural, educational, and technological barriers.
- 4) Individuals and, often, their families, do not explore their options until they are in crisis mode.
- 5) Cost prohibitions associated with good nutrition, medical care, prescription drugs, transportation, and other essential services limit many older individuals in accessing the care they need.

- 6) There is a general lack of understanding on what legal and protective services are available.
- 7) There is a lack of resources within PDA and at the local level (AAAs) to adequately address protective services issues.
- 8) Attitudes within law enforcement, the courts, and sometimes among older individuals themselves lead to lax enforcement of protective services laws.
- 9) It is difficult to fund guardianship services and the process itself lacks safeguards.
- 10) HUD and other publicly-funded housing intended as congregate communities designed to allow seniors to age in place have now become places of fear for some of these individuals, as other residents have significant mental health and drug and alcohol abuse issues. As a result, many of these residents are unable or unwilling to get out and get the services they need.
- 11) Funding continues to decrease for drug and alcohol intervention and treatment.
- 12) Both doctors and their patients are hesitant to discuss end of life issues.
- 13) In general, education of healthcare providers on long-term care issues is needed.
- 14) There is a lack of communication, sharing, and collaboration between those in the community and institutional care facilities.

Opportunities and/or Solutions

- 1) Collectivize and combine resource sharing among state-level agencies (PDA, DPW, and the Department of Health). Work in concert at the department level to coordinate the use of the 211 system to deliver a strong, consistent message, talking points, and where to direct people.
- 2) Assign one agency to monitor programs to facilitate easier record keeping and compliance.
- 3) Help local agencies better develop multidisciplinary plans that brings in all of the services necessary (e.g., aging services plus drug and alcohol plus mental health).
- 4) Use a variety of mechanisms (in addition to mass media outlets) to disseminate information on the range of programs and services available. These mechanisms can include barbershops, hair salons, tavern, doctor's offices, pharmacies, grocery stores, kiosks at casinos, libraries, and other venues outside of senior centers where more active seniors tend to go. Engage the staff at these sites (as appropriate) to assist in educating seniors. Coordinate these programs with local organization that might have already implemented similar initiatives (including the development of speaker's bureaus).
- 5) Facilitate and support local partnering opportunities (e.g., banks, financial advisors, for-profit organizations) that support this information sharing. Also, engage employee assistance agencies. PDA and AAAs can work with these agencies to help direct people.
- 6) Reinforce communication efforts at where seniors of all abilities congregate, such as senior centers, health fairs, health expos, tax preparation event, and retirement seminars. These venues could serve as forums where aging services organizations work collectively to help with staffing and costs. Provide information at crisis points, such as hospitals and rehab facilities.
- 7) Employ technology in getting the message across (e.g., tunnel monitor in hospitals, e-newsletters). Disseminate information to caregivers who may be in a better position to access information technology.
- 8) Continue to build on the new lottery campaign, which delivers a very crisp message. Target outreach and education with cultural sensitivity and diversity of population in mind. People need to get information from an organization they trust.

- 9) Build a database for AAAs and other agencies of educational strategies that work in Pennsylvania and beyond. Tap into the resources of Pennsylvania's universities (who are already involved in the development of a number of evidence-based programs to support the aging network). Explore what private organizations, such as AARP and RSVP, are doing to educate their members and piggyback on these efforts.
- 10) Promote and support local programs that work with employers on elder care and long-term planning for their employees.
- 11) Provide continuing support to caregivers. Reach out with local organizations to tap into opportunities to meet with caregivers, such as employer-sponsored workshops.
- 12) Enhance senior center programming to provide a more robust, diverse environment that will draw greater participation. Offer more choices and variety in congregate meals, and develop enticing and interesting opportunities for health and fitness.
- 13) Continue funding the farmer's market voucher program but provide assistance to AAAs in administering the program. In addition, explore mechanisms for cost sharing, such as working with local food cooperatives, agricultural enterprises, and community gardens, to support this initiative and other nutrition programs.
- 14) Expand access to and nutritional content of home delivered meals programs. Work with DPW and other to allow more flexibility for individual in spending money allocated for food.
- 15) Ramp up the staffing and financial resources at the state level for protective services (including forensic accounting), while eliminating redundancy between AAAs and other local organization in investigations. Strength and expand elder abuse task forces and the Ombudsman program as a means to forge relationships with law enforcement and district attorneys for joint investigation and prosecution. Create financial SWAT teams comprised of volunteers who will share their expertise and perhaps explore scamming trends. Enlist the assistance of experts in banking and insurance.
- 16) Develop a friction-free reporting system. The EIM system (like HCSYS) is difficult to use; the Department of Health has a much better system.
- 17) Provide incentives to build better coordination between licensing agencies, local law enforcement, and the judicial system. Educate local government officials, law enforcement, and the courts on the obligation to provide protective services and the role of protective services agencies. Reach out to universities (such as Temple) for training. Extend reporting requirements beyond those who work in long-term living (such as home care agencies and volunteer organizations) to report suspected elder abuse (similar to what's required for children).
- 18) Strengthen guardianship programs by instituting more stringent guidelines, training, and protocols (including background checks), especially for individuals for whom the family is providing the care. However, build awareness that guardianship should be a measure of last resort.
- 19) Provide state funding and assistance in the preparation of living wills and powers of attorney, as well as access to guardianship services (at a minimum and consistent from county-to-county). Tap into volunteer resources (such as RSVP and local bar associations) to help with expenses. Provide an online link to forms. Add link for people to donate their bodies (can save money on funeral costs).
- 20) Examine how the state can expand its legal services to include estate planning, fiduciary responsibilities, home and property protection, utilities and consumer protection, contractor fraud, tax problems, and issues around waivers (including nursing home resident's rights).

- 21) Encourage open discussion with individuals (and their caregivers) about long-term care and end of life issues (including financial considerations). Bring physicians and healthcare providers, AAAs, and case managers into the discussion. Help older individuals “sort out” what they have before crisis strikes.
- 22) Expedite the enrollment process to streamline hospital discharge into HCBS. Build on current models for care transitions programs, discharge planning and coordination with hospital partners Expand Community Choice throughout the state. Bring long-term care providers to the table to strengthen communication, sharing, and collaboration between those in the community and those behind institutional walls. In general, do more to raise awareness among front-line providers (such as physicians, physical therapists, and occupational therapists) about the services and programs that are available for older individuals.
- 23) Expand the revenue base use non-traditional sources (such as public/private partnerships). Find a way to offer private pay service (with unbiased counseling).
- 24) Educate providers on the need for drug and alcohol screening.
- 25) Provide more outreach to the homeless through social workers and by eliminating the stigma of nursing home care and subsidized housing.
- 26) Encourage programs that promote early intervention and treatment of behavioral health issues.
- 27) Examine the connections between different ways people will live in a healthy community plan. Look at models and work with local governments on providing the infrastructure (including transportation and housing) to ensure people can live and thrive in the community.
- 28) Ensure that PDA is the leading, most visible advocate for older individuals and those with disabilities at the department level and throughout the state. Share expertise to other state agencies. Encourage the continued development of Human Service Collaborative boards throughout the state, with AAA representation.
- 29) Do more to support AAAs and ADRCs.
- 30) Ensure that resources and supports are available for baby boomers with special needs with older parents.
- 31) Conduct asset testing of all state programs, and ensure that every dollar that is matchable will be matched.

“Systemic” or Cross-Cutting Issues

- Senior centers serve a valuable function and must be revitalized for a new generation of older adults with diverse interests.
- Waiver requirements should be simplified and made consistent across waivers wherever possible.
- There is a critical need for “care navigators” to guide individuals through the maze of services and programs available, and to strengthen care transition.
- Technology offers significant opportunities for efficiency and appropriateness (e.g., automated dosing, telehealth monitoring systems) in care delivery and in information sharing among service providers.
- The state must recognize the intrinsic link between housing and transportation in successfully accessing HCBS services.
- Communications and educational materials must be calibrated to the cultural, linguistic, educational, and generational differences among target groups.
- Communication of programs and services must be enhanced at all levels.

- The state must tap into the dynamic, evidence-based research and programs developed by its colleges and universities, as well as explore the numerous innovative local models developed by public and private agencies that service the aging network.
- Healthcare providers (including physicians, social workers, and hospital discharge planners) must be better educated in issues related to geriatric care. Further, individuals must have greater access to professional services related to such care (including behavioral health care).
- Advocacy initiatives for older individuals and the disabled must be expanded, particularly for those who have chronic diseases, brain injuries, or visual or hearing impairments.
- Agencies and other providers must understand that a “one size fits all” approach fails to recognize that perceptions and attitudes vary widely among those who participate in programs and services.
- Systems and programs should be examined to eliminate redundancies and promote streamlining of service delivery and funding.
- Cost-sharing (e.g., public-private partnerships, fee-for-service) and other models offer significant opportunities for expanding programs, both for the populations currently served by the aging network and for those who may currently be ineligible due to income limitations.
- Individuals have to be educated on planning for their own futures, rather than entering the system in crisis mode.
- Support systems for caregivers must be strengthened to enable this informal means of support to function as effectively as possible.
- It is imperative to understand and follow the wishes of the individual to provide the appropriate level of care (especially at end of life). To enable this, individuals must be made aware of and provided assistance in preparing living wills and powers of attorney.
- The state must do more to ensure appropriate legal and protective services for those in the aging services network. This includes cooperation building with and education of law enforcement professionals and those in the judicial system. It also includes addressing guardianship.