

What Do Older Adults and People with Disabilities Need?

Answers to Open-Ended Questions from DSHS' Aging and Long-Term Support Administration State Plan on Aging Survey

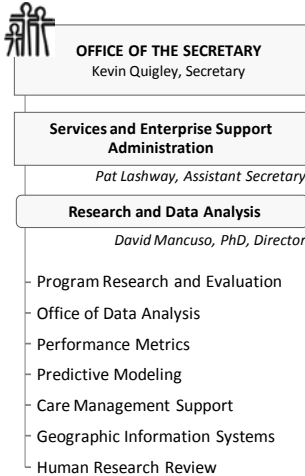


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*Report findings are presented in collaboration with Rosemary Biggins,
State Unit on Aging Program Manager, DSHS Aging and Disability
Services Administration*



What Do Older Adults and People with Disabilities Need?

ANSWERS TO OPEN-ENDED QUESTIONS FROM ALTSA STATE PLAN ON AGING SURVEY

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In collaboration with Rosemary Biggins, State Unit on Aging Program Manager, DSHS Aging and Disability Services Administration

THIS REPORT discusses the worries, fears, plans, and program desires revealed in a survey of Washington State residents who are aging and/or living with disabilities, and their caregivers.

The survey reveals that people know they will not always be able to care for themselves and their present homes. They plan to modify or downsize their homes when needed. They worry about isolation, boredom and lack of meaningful activities when they can no longer drive. They worry about not being able to find or afford trustworthy caregivers in the home. They fear being alone and needing help in an emergency – and they fear losing their homes, independence and privacy if they need assisted living. They long for closeness to their families – and they fear both burdening them and being neglected or exploited by them. Most of all, they fear the loss of control, independence and ability to make their own care decisions if their cognitive abilities and memories decline.

The program desires of respondents are clear responses to these fears and concerns. They would like help with home modifications for safety, with routine home, yard maintenance, and meals, and with transportation to both needed appointments and community activities when they can no longer drive. They would like to choose and pay for their own caregivers in their own homes, keep their pets near them, and have enough in-home care hours to assure safety. They would like respite, support and education for family caregivers. They would like advocates to assist in their care decisions, particularly assisted living decisions, and people to help them pay bills and manage medical paperwork. They would like to be part of family, friend, and community networks of care.

Survey Facts

The report draws on a content analysis of all the responses to six open-ended questions from a July 2014 survey conducted by the DSHS Aging and Long Term Services Administration (ALTSA). It was distributed both on-line and on paper, through Home and Community Services field offices and Area Agencies on Aging. 1,607 people answered at least one survey question – but only about half answered one or more of the open-ended questions that form this report.



SECTION 1 discusses answers from “potential clients and family caregivers” – mostly people sixty or older, and/or with disabilities, and/or family caregivers (paid or unpaid). Many were **both** potential clients and caregivers. About four out of five respondents were in this group.

SECTION 2 discusses answers from the remaining one in five respondents – younger, non-disabled aging and disability professionals who were not caring for family members.

APPENDIX A shows the supporting content analysis tables for all six questions.

SECTION 1 SUMMARY

Most Frequent Answers from Potential Clients and Family Caregivers

1. If Washington State could improve services for people with memory loss or Alzheimer's disease/dementia, what would be the best first step? (n = 539)

- Education (for caregivers, families, professionals and the public) **35%**
- Family and caregiver supports (respite, education) **21%**
- Community services (earlier diagnosis, adult day programs) **19%**
- Cost, affordability, funding and subsidy issues **19%**

2. What are the most needed programs and services that allow older persons to live where they want to live? (n = 668)

- In-home supports (caregivers, chore workers, meals, visits from providers) **63%**
- Transportation **22%**
- Community services (recreation and social, adult day programs) **20%**

3. What other programs or services would you like to see for older persons and/or persons with disabilities? (n = 512)

- Community services (recreation, social) **47%**
- In-home supports (caregivers) **22%**
- Good service planning and choices **15%**

4. As you age, what do you think would be the most help in allowing you to remain in your own home? (n = 609)

- In-home supports (caregivers, chore workers, meals, home modifications) **69%**
- Community services (family and friend network to help) **23%**
- Good service planning and choices **17%**
- More and better transportation **16%**

5. As you age, what is your greatest worry/fear as you think about staying independent and in your own home? (n = 692)

- Not having enough money for life and services **26%**
- Being alone, isolated, lonely **14%**
- Finding good, reliable, trustworthy caregivers **13%**

6. Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State. (n = 343)

- Community services (activities that are social, fun, feel worthwhile) **28%**
- Cost, affordability, funding and subsidy issues **28%**
- Good service planning and choice **15%**

SECTION 2 SUMMARY

Most Frequent Answers from Service Professionals Only

1. If Washington State could improve services for people with memory loss or Alzheimer's disease/dementia, what would be the best first step to do so? (n = 102)

- Education (for caregivers, families, professionals and the public) **46%**
- Cost, affordability, funding and subsidy issues **23%**
- Family and caregiver supports (respite, education) **21%**

2. What are the most needed programs and services that allow older persons to live where they want to live? (n = 119)

- In-home supports (caregivers, chore workers, meals, visits from providers) **70%**
- Community services (recreation and social, adult day programs) **21%**
- Transportation **18%**

3. What other programs or services would you like to see for older persons and/or persons with disabilities? (n = 98)

- Community services (recreation, social) **48%**
- In-home supports **20%**
- Cost, affordability, funding and subsidy issues **14%**

4. As you age, what do you think would be the most help in allowing you to remain in your own home? (n = 123)

- In-home supports (caregivers, chore workers, meals, home modifications) **63%**
- Community services (family and friend network to help) **20%**
- Good service planning and choices **19%**

5. As you age, what is your greatest worry/fear as you think about staying independent and in your own home? (n = 105)

- Not having enough money for life and services **29%**
- Finding good, reliable, trustworthy caregivers **20%**
- Being alone, isolated, lonely, losing friends **13%**

6. Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State. (n = 55)

- Cost, affordability, funding and subsidy issues **29%**
- In-home Supports **27%**
- Community Services **25%**

The answers given by aging and disability service professionals were similar to those of the potential clients and family caregivers – but there were some themes that emerged more strongly among the professional group. Cost, affordability, funding and subsidy issues were a stronger focus for service professionals. The professional group was also more concerned about system failures and service cuts, about the ability to keep trusted caregivers, and about abuse, neglect and exploitation.

SECTION 1

Potential Clients and Families

Q.1 If Washington State could improve services for people with memory loss/Alzheimer's disease/dementia, what would be the first step to do so?

539 people answered this question. Education (for caregivers, families, professional and the public) and increased support for family caregivers were the strongest emphases in their answers.

Over one in three people (35%) recommended expanded education and training—to patients and families (19%), health and human service professionals (8%), and the public (6%).

- “To help family members with education, findings, outside help.”
- “Educate people. This type of problem is very hard on the person inflicted. The worst thing to do is not know how to react. Understanding is key.”
- “Get physicians, nurse practitioners, primary care providers up to speed about dementia and resources available for patients and care givers.”
- “Professional and on-going education on dementia is key: what it is and how to work with individuals diagnosed and with the care partners. Too many providers consider themselves experts on dementia, when they are not. It takes on-going and evidence-based trainings, provided by true experts in the field (with a proven track record) to stay on top of the latest in this ever-evolving arena.”
- “We need a great deal more education and awareness on this disease. There is much misunderstanding about the illness and the toll it takes on the caregivers.”
- “Education to the 30-55 year olds, as they will be the ones caring for their parents.”

Over one in five people (21%) discussed family involvement, support, and respite.

- “Help for caregivers. Respite care, chore services. The isolation of caregivers and the elderly is terrible. Life shouldn't revolve around illness ... so support groups are helpful.”
- “Support and help the spouse/caregiver from the onset of the illness until the patient needs to be institutionalized.”
- “Provide help for the caregivers. It is draining on them, and frustrating to have their loved one “gone”. Their body is there, but their mind is gone along with the person they used to be.”
- “Family caregiver supports, including respite; In-home personal care; In-home chore services. The above items are needed in order for the caregiver to be able to keep their loved one at home.”

Almost one in five people (19%) suggested that added funding would be needed, including increases in caregiver hours, increased rates for specialized facilities and more help for families.

- “Help with access to secured and unsecured facilities, rates are too low and people are not accepted when on Medicaid.”
- “Improve capacity for increased hours of personal care-so clients can benefit from routine in their own homes, as long as possible.”
- “Giving caregivers more hours and pay to deal with clients before it gets to nursing home facilities (only as a last resort).”

Almost one in five people (19%) suggested expanded community services, particularly adult day programs and earlier screening and diagnosis.

- “Greater access to adult day programs that are affordable, supportive and provide respite at the same time!”
- “Increase reimbursement for adult day services and consider changing from “day” to “hour.”

- “Provide rural communities with adult day care programs in a hub.”
- “Early diagnosis and family education about what to do to address disease progression.”

Less frequent community suggestions included prevention, more memory loss programs, more research, and better health and mental health care.

17% suggested in-home services, particularly caregiving and chore services.

- “One-on-one caregivers. I take care of my mother and can't imagine not having someone with her at all times.”
- “Allow people to get in-home services that are more chore-like than personal care—many are frail/forgetful and can't do chores but can physically take care of themselves.”
- “Trained live-in assistance program that offers room, board & small stipend in exchange for care.”

13% suggested improved service planning and case management.

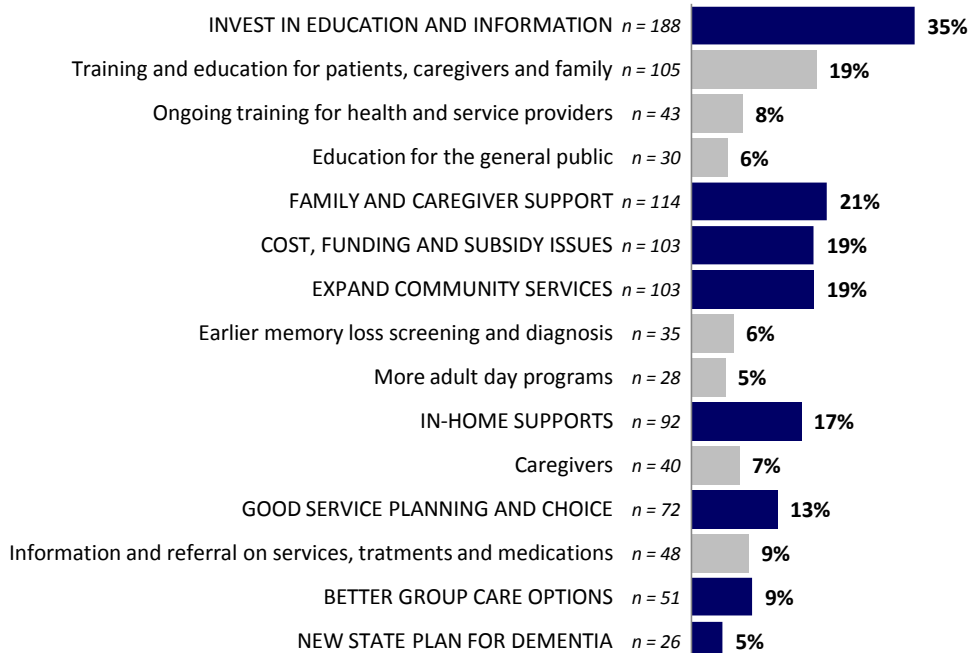
- “Make the process easier. There is so much financial and medical paperwork. Some people are more friendly and helpful than other people.”
- “Memory Loss Navigator for services available for family.”
- “Use media to make sure individuals know what is available and how to access them. A single phone number and email address for help would be perfect.”

9% suggested need for more assisted living facilities for persons with memory loss—particularly ones accepting Medicaid reimbursement—and closing down poor ones.

Eleven people discussed treating people with respect and dignity, serving them in their own language and culture and in an accessible manner, or ensuring service availability in rural areas. Three people mentioned protection from abuse and nine asked for better quality assurance and program monitoring. Three people suggested closing down nursing homes.

26 people assumed that a new state plan was needed (probably in response to an earlier fixed-response question about a new state plan) and suggested ways to gather information, build public support and estimate the prevalence of dementia and memory loss.

Q.1 If Washington State could improve services for people with memory loss/Alzheimer's disease/dementia, what would be the best first step to do so? TOTAL = 539



SOURCE: AL TSA Home and Community Services, July 2014

Q.2 What are the most needed programs and services that allow older persons to live where they want to live?

668 people answered this question. In-home services, transportation and community services were the strongest emphases in their answers.

Almost two in three people (63%) suggested one or more In-home supports. Most frequent ideas were well-trained, trustworthy caregivers, help managing house chores and home-delivered meals.

- “In-home caregivers who love what they do.”
- “Having a caregiver with the knowledge to take care of me.”
- “Trustworthy caregiver support.”
- “Sustainable in-home services, such as Elders Caring for Elders.”
- “Help with bathing, dressing, and medication management.”
- “Assistance in daily household chores—cooking, cleaning and companionship.”
- “Someone to come and do handyman work, like repair things.”
- “In home care that fluctuates with the increasing or decreasing needs as they present themselves.”
- “Well trained, qualified in-home care, a means to help elderly understand when they are unable to drive a car any longer, take care of meals, take medications, clean house, do yard work.”
- “Help in home and regular visits to home by persons who can evaluate the quality of life there.”

Less frequent home-care suggestions included in-home visits from medical professionals and case managers; company and social interaction; safety checks; medication management; dementia programs; home monitoring; safety checks and pet care.

Over one in five people (22%) discussed transportation improvements.

- “Transportation is the key to remaining at home when we can no longer drive.”
- “For rural areas we need more allotted miles per month!”
- “Transportation to all services including social. I want to visit my friend of 50 years—there should be transportation for that!”

One in five people (20%) suggested one or more community services. Most frequent were company, social interaction, friends, activities and recreation and adult day centers.

- “Social/community activities for them to interact.”
- “Social outlets within a reasonable distance—maybe a group that rotates areas.”
- “As caregiver to my wife, I am finding the adult day center most helpful.”
- “Adult day centers with trained and knowledgeable staff, not just ‘baby sitters’.”
- “Adult Daycare is indispensable. The programs should be expanded, they are much cheaper than long-term care, but they seem to be getting cut left and right, if they exist at all.”

Less frequent community care suggestions included: group meals, meal planning and nutrition classes, shopping, medical and health care improvements, exercise and fitness, financial assistance and bill-paying, pre-planning for old age, mental health, support groups, senior centers, pet care, legal services, and memory care programs.

17% suggested some form of financial assistance—including grants, expansions of paid services or low-income subsidies.

- “Fiscal assistance to pay for needed services.”
- “More affordable housing close to services, shopping, parks and transportation.”
- “More in-home care hours—current amounts don’t keep people in their homes safely.”
- “Case management, funding for low income housing choices and transportation for people who can no longer drive.”

13% discussed needed changes in learning about, choosing, authorizing and managing services while respecting the individual's independence and rights.

- “First they or their caregivers need to know where to find help or what is available.”
- “They need someone to coordinate services for the person and family.”
- “COPEs—and case managers or social workers that work TOGETHER, a one-stop shop.”
- “Independent living skills to re-establish that the individual is in charge of their life.”

13% discussed services to family caregivers.

- “Mental health support for the caregiver.”
- “Respite for the family.”
- “Educate the family how to handle a person with dementia.”

6% discussed improvements in safety and accessibility.

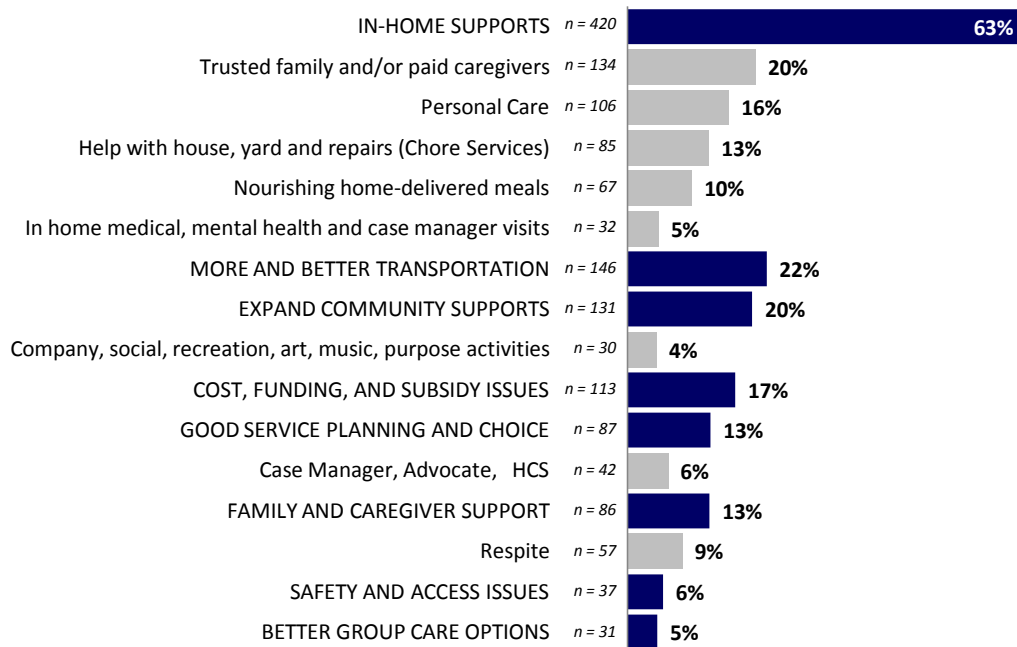
- “Modify homes so people can remain there as long as possible.”
- “Emergency alert monitors that are worn on the person.”

5% discussed the need for more or better assisted living facilities.

- “Adult family home to age in place with a care team.”
- “Availability of more adult family homes and assisted livings.”

12 people discussed treating people with respect and dignity, in their own language, in an accessible manner. Four mentioned protection from abuse.

Q.2 What are the most needed programs and services that allow older persons to live where they want to live? In-home services, transportation and community services were most often suggested. TOTAL = 668



SOURCE: AL TSA Home and Community Services, July 2014.

Q.3 What other programs or services would you like to see for older persons and/or persons with disabilities?

512 people answered this question. Social interaction, recreation, fitness and community engagement were the strongest emphasis in their answers.

Community services were suggested by almost one in two people (47%). Most frequent ideas were the importance of company, interaction, recreation and activities that made people feel useful (22%). Also frequently mentioned were fitness, gentle exercise and adult day programs (6%)

- “Programs/services that connect people to the arts and music.”
- “Converting senior centers to “intergenerational” centers of learning, crafting and activity.”
- “More safe places for older adults to gather and socialize, more ways for older adults and adults with disabilities to be useful.”
- “Opportunities for older persons to become/stay actively involved in community concerns and/or opportunities for ‘late-life-learning’.”
- “Maybe a friend for life program, a match up with a youth person who visits a couple times a week through a school program or pet companion at home. Stop the isolation.”
- “Recreational facilitator—so many seniors have limited mobility and can't get out much, many are lonely and depressed.”
- “Lists of social opportunities in area appropriate for age group and levels of disabilities.”
- “Community engagement programming (movie nights, volunteer opportunities for people with dementia) and social events (momentia movement).”
- “Jobs and social activities for people with disabilities.”
- “Some type of youth volunteer/mentorship program that gives elderly persons a chance to pass on their knowledge and life lessons to the next generation and feel a sense of community as well as a sense of contribution to their society.”
- “Self-care education and exercise programs.”
- “Exercise programs, affordable gym memberships.”
- “Lists of light exercise opportunities for older person and care giver.”
- “More emphasis on healthy living, including activities.”
- “More exercise options for people in chairs.”

Less frequent community care suggestions included: healthy group meals, meal planning and nutrition classes, shopping help, medical and health care improvements, financial assistance and bill-paying, pre-planning for old age, mental health, Books on Wheels, outdoor outings, support groups, senior centers, pet care, legal services, and memory care programs.

- “Increased access to mental health and chemical dependency programs. Programs such as Project Pride short term case management and Catholic Community Services low-cost counseling services are no longer available and this has been a large loss.”

One in five (22%) included at least one In-home service. Most frequently mentioned were trusted paid and family caregivers and personal care workers (6%).

- “The ability to hire a friend or family member to help you with personal care at home.”
- “Caregivers.”
- “Extensive 1:1 companionship services, implemented by caregivers.”
- “Tele-health programs that allow seniors and their caregivers to monitor health issues without having to leave to see an MD.”

Good service planning, particularly around information and referral, was suggested by 15%.

- “More info getting out there. So many people don’t know where and how to find help.”

- “Make programs more available and accessible, a better informed client base.”
- “Support for care managers who know my needs, the resources available to me, and help in accessing and paying for needed services.”
- “Client advocacy, and a navigator.”

Transportation, often to facilitate community activities, was suggested by 14%.

- “A program that meets their needs for getting to appointments, personal services such as getting their hair taken care of and feel like they are human beings.”
- “Community access that takes clients out to do something fun—movies, bowling, etc.”
- “Senior centers with transportation provided with a variety of activities.”

Financial assistance, subsidies or funding increases was suggested by 12%

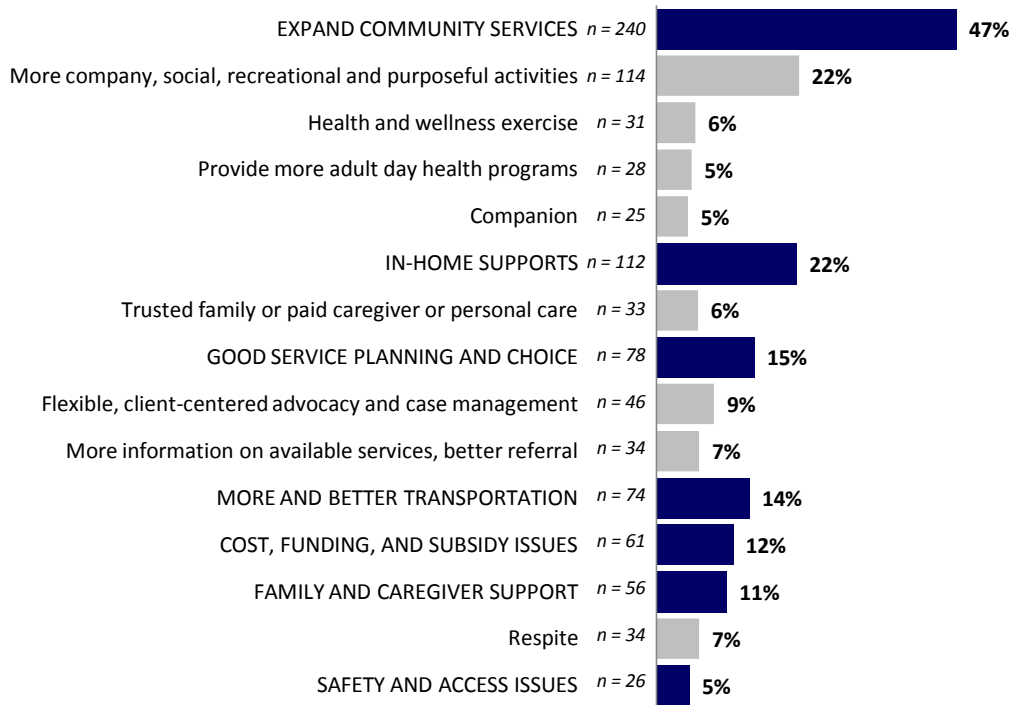
- “Additional funding from the Legislature for the 14,000 people with developmental disabilities on the wait list for services!”
- “Cash to pay for specialized equipment and services, access to adaptive technology.”
- “It would greatly help if spouses who are care givers could be paid—ease our financial burden.”

Supports to family caregivers was discussed by 11%.

- “Support groups in different languages for the elder and their families, especially for dementia.”
- “More education directed to family members and the social network.”
- “Regular respite for family caregivers.”

26 people discussed improved safety and access. 20 people discussed treating people with respect and dignity, in their own language, in an accessible manner. 16 people suggested improved group care. Six discussed services in rural areas. Six mentioned protection from abuse.

Q.3 What other programs or services would you like to see for older persons and/or persons with disabilities? Community, social activities, in-home and transportation were most often suggested. TOTAL = 512



SOURCE: AL TSA Home and Community Services, July 2014.

Q.4 As you age, what do you think would be the most help in allowing you to remain in your own home?

609 people answered this question. Almost seven in ten (69%) suggested in-home supports (frequent mentions were caregivers, chore workers, home modifications or downsizing, and home-delivered meals). Community supports were also suggested, especially local networks of family and/or friends.

Almost seven in ten people (69%) included at least one In-home support. Most frequent were:

Well-trained, reliable and trustworthy caregivers, both from the family and outside (22%).

- “Having a qualified caregivers take care of me.”
- “Continuity in caregivers, supportive living partners in the home.”
- “Reliable caregivers. Definition of reliable caregivers: they come on time every time they are scheduled to come, they do all of the tasks they are scheduled to do, they speak English (in my case) and they make reasonable accommodations for my disabilities, just like they would have to do in any other job.”

Help managing daily and occasional chores around the house and yard (22%).

- “In-home assistance such as housekeeping, laundry, shopping, cooking.”
- “Help with yard work, housework and maintenance of my home.”
- “Help with housework, yard work, snow removal.”

Home modifications or downsizing (11%).

- “Get my home more disabled friendly. Doors, ramps installed.”
- “Preparing my home so that I can live on one floor if stairs become an issue.”
- “Maybe folks need help transitioning to smaller living situations, less square footage, but with support services nearby. We need small villages or something like that.”
- “Downsizing to a manageable place for my capabilities.”

Home-delivered meals (10%).

Less frequent home-care suggestions included safety and oversight checks and medication management.

One or more types of community services were suggested by over one in five people (23%). A strong theme in the comments was the importance of local friend and family networks (7%).

- “Friends, family, connection to my community and having pets to love me always.”
- “A family-style provision of care, with a support network that helps with care needs.”
- “A community of friends and helpers to care for me and for me to care for. Possibly room-mate matching as I become less able to care for myself.”
- “I would have family members close by to assist me, and be with me.”
- “Getting a couple of friends to move in and we all share the costs and have each other to bounce off of.”
- “Nearby family members who, supported by the system as needed, can provide long-term care.”
- “Having family and friends close by for companionship, and trustworthy, intelligent caregivers available for tasks that I could no longer safely perform.”
- “The Village Model.”

Other community supports mentioned included adult day programs, wellness activities, recreation and social events, planning for aging, legal help, financial planning and bill-paying, good health care, mental health care, support groups, and senior centers.

17% discussed needed changes in learning about, choosing, authorizing and managing services while respecting the individual's choices and understanding their capabilities.

- “Staying empowered to make my own choices.”
- “Having someone to help me set things up for my care according to my medical needs and mentality.”
- “Flexible specific care to the changing needs either increasing or decreasing in intensity.”
- “Having someone to help develop a plan would be the best service – and an individual to contact if a problem arises.”
- “Being treated with dignity and respect and being included in the decision making within the confines of my mental state at the time the decision making is being done.”

16% included transportation in their lists of what would be needed.

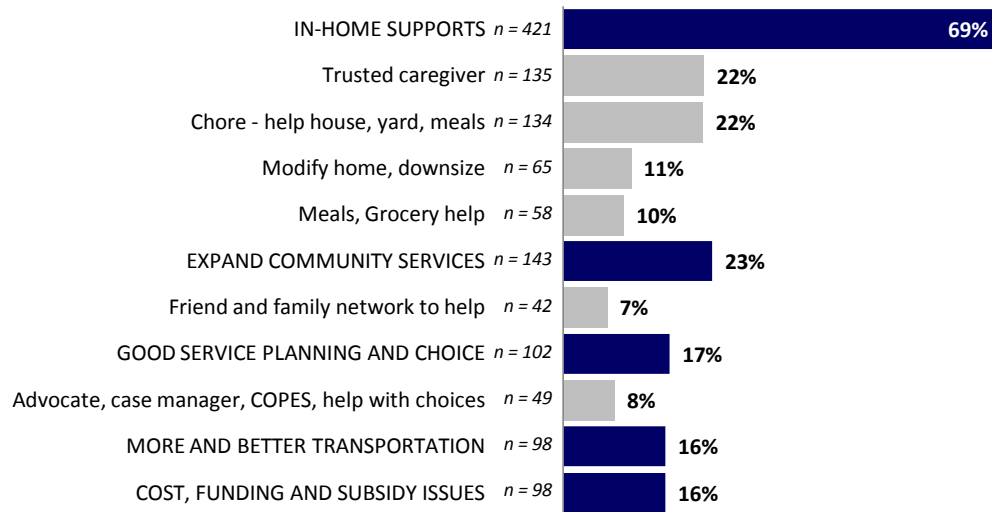
- “I may in time need access to a ride to the doctor’s office, grocery store or”
- “Access to easy, affordable transportation.”
- “Inexpensive transportation and easy access to bus routes.”

Financial issues were discussed by 16%, often in relation to housing and medical costs.

- “Financial planning. Allowing me to afford the services designed to help me stay at home or live where I'd like to.”
- “Financial planning—I am struggling paying bills each month & am not always aware what help is available.”
- “COPES in home with housing and medical expenses of the well spouse taken into consideration. I want a budget where I can decide what spouse and I need so that I can continue to pay for home expenses and care for spouse.”
- “A safe environment, low cost housing and utilities, neighborhood safety, family and friends.”
- “Be able to secure affordable in-home care for myself and my family as I age in place.”
- “More complete health care coverage for drugs and for cochlear implants.”

33 people discussed caregiver support, including respite. Three said they did not want to go to a nursing home unless absolutely necessary.

Q.4 As you age, what do you think would be the most help in allowing you to remain in your own home? *In-home services including caregivers, chore-workers, meals and home modifications or downsizing; community services including friend and family networks; flexible service planning, transport and funding most often suggested. TOTAL = 609*



SOURCE: AL TSA Home and Community Services, July 2014.

Q.5 As you age, what is your greatest worry/fear as you think about staying independent and in your own home?

692 people answered this question. 26% worried about not having enough money. Other concerns were: finding good caregivers, being isolated and alone, falling, inability to care for self and home, loss of independence, being forced into a nursing home, inability to drive, ill health, dementia, no trustworthy family nearby, losing their home, inability to walk, not being found in an emergency.

Not having enough money to pay for living and needed services (26%).

- “That I would run out of money and have to live in a facility.”
- “I will not be able to afford to stay home and pay for personal care at the same time.”
- “Ability to pay for supplemental/respite caregiver services, on a very limited budget.”
- “How can I afford to stay home with my Social security pension?”
- “Money...it costs a lot of money to keep someone in your home with special needs, let alone two individuals with special needs, especially if their care keeps you from holding a job. I really don't want to be a financial burden to anyone.”

Being alone, isolated, with no caring person near (14%).

- “Isolation from others due to not being able to get around on my own.”
- “What is my greatest fear in my home is no one with me.”
- “Not having at least one very trustworthy and smart person that cares about my well-being to visit frequently and talk to me.”

Not finding capable, trustworthy caregivers and helpers (13%).

- “Running out of money and having to have untrained caregivers in my home doing care.”
- “That I won't have affordable housing or consistent, reliable caregivers to stay in it.”

Falling, losing balance, being injured (12%).

- “I believe it is a toss up between being alone and falling.”
- “Concern about falling and the injury that can come with it. Many who are seriously injured from a fall eventually never recover.”

Not being able to care for my home (12%).

- “Being able to care for my home, going up and down stairs to the basement.”
- “Not being able to manage the housekeeping and yardwork, or get on a ladder.”

Loss of control, forced residential care, inability to care for self, or drive, poor health (9% each).

- “Becoming too disabled to live independently.”
- “Not able to drive and take care of myself.”
- “My worst fear is losing the ability to drive; becoming isolated and "shut in" is a real possibility.”
- “One thing that concerns me is prematurely being placed in a residential care system.”
- “Being unable to continue, and being relegated to a nursing facility if I get sick.”
- “That my loved ones do not know how to advocate for what I truly want done or need done. That I will not be able to live at home due to I need a certain device ... because I do not have the means or the foresight to have this remodeled years before the need arose.”

Confusion, dementia, memory loss, mental incapacity (8%).

- “Dementia ... losing my mind and abilities is what causes the most fear.”
- “Cognitive decline that might result in accidents, safety hazards.”
- “Loss of memory.”

Family, no nearby family, cannot trust family, don't want to burden family (7%).

- “Being a burden to my children.”
- “No family nearby.”
- “That my family rejects me or can't be bothered and put me away in a nursing home.”

Losing home, lack of mobility, not being found after a major medical event (5% each).

- “Having to leave my home.”
- “Losing my home due to tax increases.”
- “Mobility—I have acute sciatica and damage to my lower back.”
- “Living alone and have something like a stroke or fall and not being able to contact anyone.”

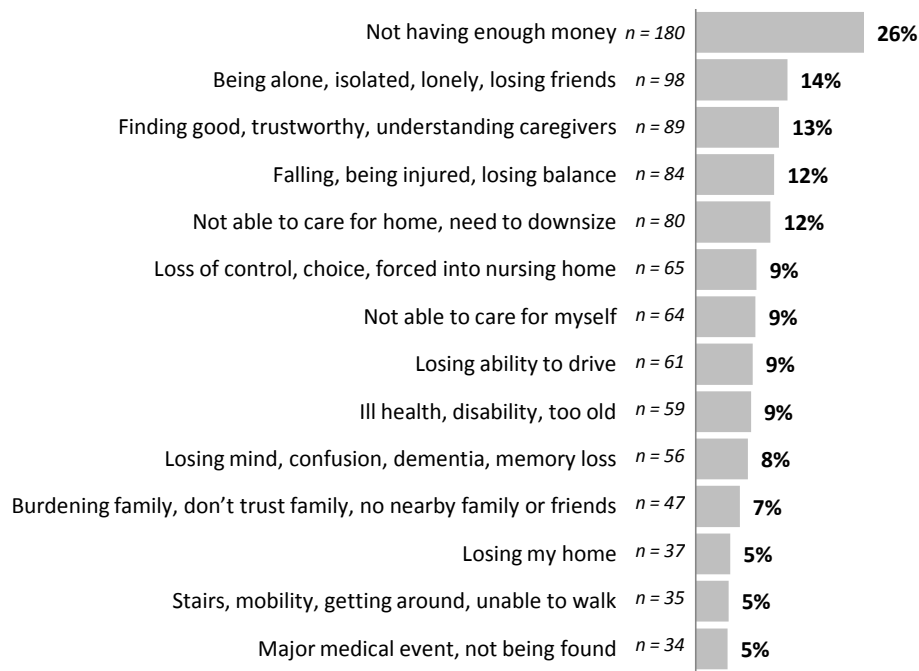
Other fears mentioned by 10 to 25 people included service cuts and system failures, safety, care of pets, nutrition, need for an advocate, abuse, neglect, exploitation, care of disabled family members, not enjoying life, bad health care, depression, sensory loss, discrimination and dying alone.

- “I am most concerned that whether I stay at home, or go to a facility-- I will become marginalized and not allowed a purpose in my life – that I will be 'cared for' to the point that there will be little meaning in my day-to-day activities. That if I act out or appear distressed, I will be medicated rather than engaged.”

12 people said they didn't worry.

- “I guess I have decided to not respond with worry and fear to the facts of aging. I regard the most important critical success factor as being our ability and willingness to maintain our multi-generational alignment of goals and actions. Independence is a fallacious notion. We are all interdependent; the only question is who it is we are interdependent with. Let's stop denying the reality of lifelong interdependence.”

Q.5 As you age, what is your greatest worry/fear as you think about staying independent and in your own home? No money, isolation, no good caregivers, falling, loss of ability to care for home or self, no control or forced nursing home, not driving, ill health, confusion and dementia, family, loss of home, inability to walk were most often suggested. TOTAL = 692



SOURCE: AL TSA Home and Community Services, July 2014.

Q.6 Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State

343 people answered this question. 28% discussed community supports and 28% discussed increased funding and other cost and affordability issues. Other concerns included good service planning for choice, in-home services, caregiver supports, dignity and respect, increasing transport, and increasing assisted living options accepting Medicaid clients.

Community supports were discussed by 28%—particularly recreation and social activities and the involvement of family and friends.

- “Older persons need socializing and other activities to help them stay vital. They need to be treated as valuable members of society. They need to know their lives are important.”
- “Companionship, family involvement in an older person life, health, and well being.”
- “Please involve teens in interaction with the elderly (see the new documentary 'Cyber Seniors'.) Keep seniors active and challenged, therefore valued.”
- “Perhaps we need a way to record memories of elderly, preferably before they lose their abilities to share their past.”
- “I see that many older people do not feel needed. I want to see programs that allow others to benefit from the experience/wisdom from our elders. What about ‘adopt a grandparent’ program? For youth that need advice/love/patience?”

Other community suggestions included advance planning for aging; bill paying; improved health, mental health, vision, hearing and dental care; and new community forms.

- “For many of us, a little help in planning could go a long way to ensure safety and quality of life as we age. It would also be more cost effective.”
- “Better preparation for the ultimate decline of physical, emotional and intellectual abilities.”
- “Hearing loss affects 1 in 3 at 65. By 75, more than half have hearing loss.”
- “Deaf older persons need sign language interpreters. The deaf person struggles with communication in the nursing homes, adult family homes and rehab centers.”
- “The most important need is training for older people who are losing vision due to age-related eye disorders, such as macular degeneration, so that they can remain at home.”
- “Address loneliness and depression in geriatric adults who are otherwise healthy/stable.”
- “I would love to see a sensitive, gentle and ‘unlabeled’ mental health service to help the elderly person deal with anger, bitterness, codependent and passive aggressive behavior, and grief.”
- “A social worker on call to cope with paperwork would be a wonderful boon. The burden of untended paperwork weighs heavily on the mind. Sometimes it even makes me quite frantic with anxiety, even though I am usually a calm and even-tempered person.”
- “I am a strong believer that aging in place involves the community. The area where you live must be walkable, safe, have access to grocery stores, and housing must be affordable.”

Increased funding, changes in eligibility, or subsidies were suggested by 28%.

- “There will be MORE NEED because there are MORE SENIORS—please don't slash funding!”
- “A person cannot live on 40.00 a month in food benefits while only getting social security.”
- “People with early onset dementia have few resources available to them if they are under 62. We need more options and help!”
- “Housing cost is a huge concern. Retirement communities are great, but people can't afford them.”
- “If people are living with the folks they are taking care of, for 24/7 care, they should be paid. They don't have time for anything else and there is usually nobody to give them a day off.”
- “The CARE assessment that is currently used in assessing hours of care is weighted heavily toward the physical health of a person, with mental (dementia, etc) taking a back seat.”

Good service planning and choice were discussed by 15%.

- “A clearer explanation of benefits, less paperwork and an easier process of getting services.”
- “Independent Living Centers need to have an equal role with disabled adults.”
- “Support people as they age in a manner that respects ability and individual choice.”
- “A safe place and resources for older persons to attend and gather information, after all, if you're lucky enough to get to older person status you've probably earned it.”

In-home supports were discussed by 14%.

- “Keep the person in their own home as long as possible; nursing homes are too expensive and a person will get better care at home.”
- “We need better access to home care, better understanding of services and affordable options.”
- “Heaven help us if we focus too much on ‘staying in one's current home.’ Seniors and disabled persons want to be safe and comfortable and among friends. They want to be treated with dignity and respect. It isn't where you live, it is how you live.”

Family and caregiver support by 12%.

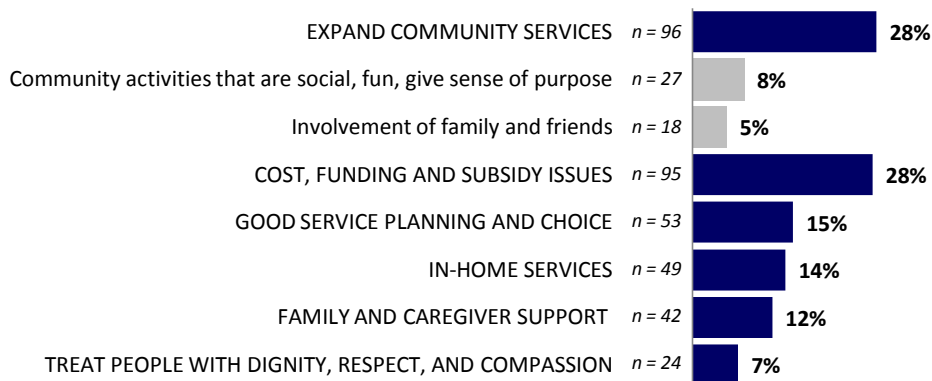
- “Need more community education on the effects of stroke, aging, memory loss, diabetes, and how family members can better take care of their elders who need help, and information for those family members about supports for home care.”
- “Respite care and support for caregivers is extremely important in preventing abuse of vulnerable people. Caregivers are a high-risk population for depression. High stress levels in caregivers contributes significantly to elder abuse.”

Dignity, respect and compassion were discussed by 7%.

- “They need to feel wanted and cared for and that all of their individual needs are taken care of with dignity and respect.”
- “Our society needs to value the wisdom held by our seniors and give the proper respect.”
- “Just because we are getting older doesn't mean we do not have a brain.”

24 people discussed the need for affordable group care options, particularly adult family homes—and 19 said no nursing homes. 15 people discussed transportation; 14 abuse protection, 11 the need for better quality oversight. 13 people said Washington State is doing a good job overall!

Q.6 Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State. Community supports, more and more flexible funding, good service planning, in-home supports, supporting family caregivers, and treating people with dignity and respect were most often suggested. TOTAL = 343



SOURCE: AL TSA Home and Community Services, July 2014.

SECTION 2

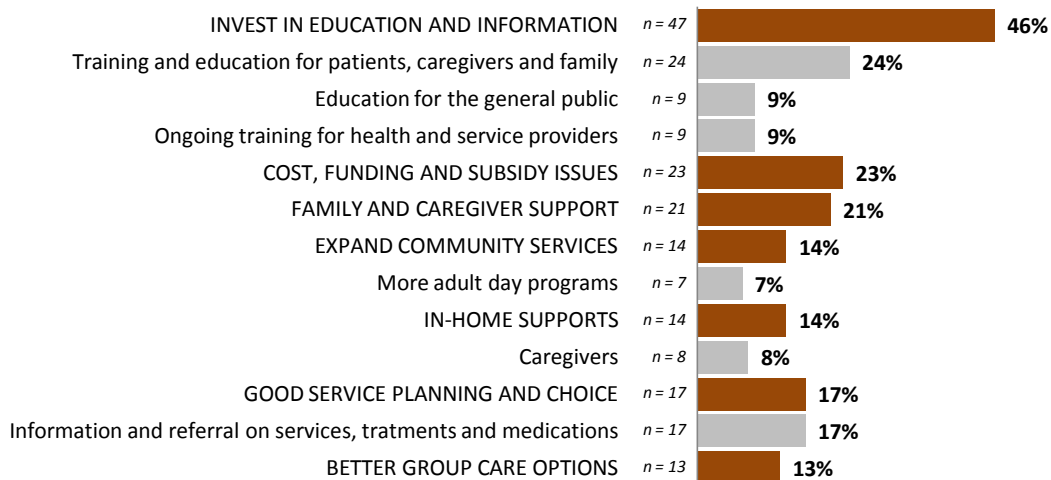
Service Professionals Only

Q.1 If Washington State could improve services for people with memory loss/Alzheimer’s/dementia, what would be the first step to do so?

102 service professionals answered this question. Education (for caregivers, families, professional and the public) and increased support for family caregivers were the strongest emphases in their answers.

- “Educating caregivers and family members much more extensively, perhaps offering a certification in such a specialty to caregivers and compensating them for their time and efforts in making the lives of those affected by such diseases much more comfortable and viable.”
- “Educate people. This type of problem is very hard on the person inflicted. The worst thing to do is not know how to react. Understanding is key.”
- “Educate physicians and pharmacists so that people with dementia can get good prescription medication programs put in place. Educate paid caregivers. Some don't know the first thing about memory loss and take things personally or judge the person with memory loss.”
- “Help for caregivers. Respite care, chore services. The isolation of caregivers and the elderly is terrible. Life shouldn't revolve around illness ... so support groups are helpful.”
- “Offer respite care to family members —caregivers suffer from stress and emotional exhaustion.”
- “Provide evidence-based treatment and adequate staffing for patients in long-term care.”
- “Develop a specialized Dementia/Alzheimer's Coordinator Unit with social workers who are thoroughly educated and experienced in all the resources available and the step-by-step process to accessing services. Should be made up of a worker from each of the following areas; financial worker; residential worker; in-home worker; county worker etc. This unit would be available to 8-5 like intake unit to assist people's questions and help with applications etc. This way family would always be able to get a hold of someone at all time to answer questions.”
- “Acknowledge that it is on par with other mental illnesses in Access to Care criteria (an "A" dx); support differential diagnosing because how you treat one dementia (e.g. Lewy Body) is different from another dementia (Alzheimer's); work to allow needed services to be paid for even if CMS won't acknowledge Case management or Care coordination as billable services; support H.R.3662 to allow LMHC and LMFT professionals to bill Medicare Part B services.”

Q.1 If Washington State could improve services for people with memory loss/Alzheimer's/dementia, what would be the best first step to do so? TOTAL = 102



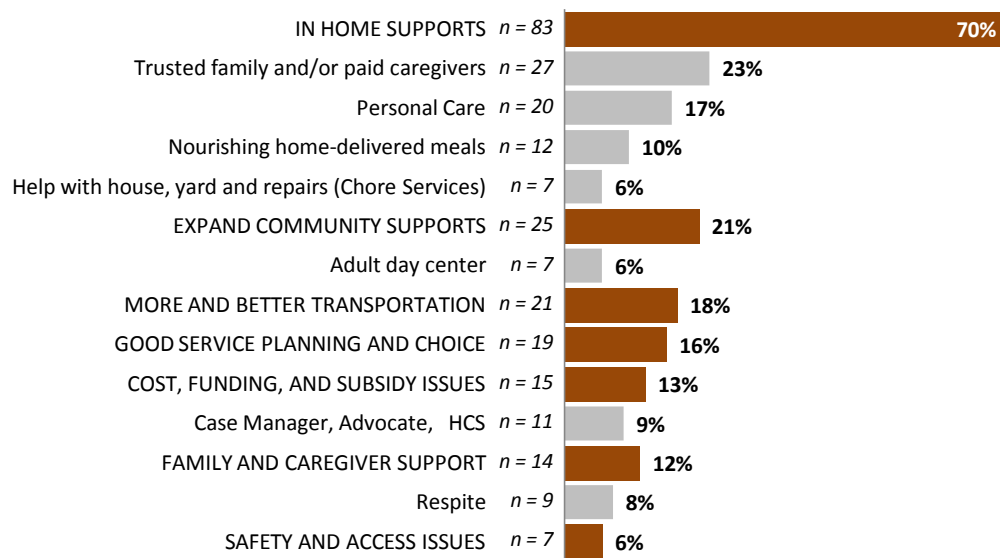
SOURCE: AL TSA Home and Community Services, July 2014.

Q.2 What are the most needed programs and services that allow older persons to live where they want to live?

119 service professionals answered this question. In-home services, community services and transportation were the strongest emphases in their answers.

- “Adults like and prefer to live either close or not far away from any family member/friend; that is the reason I don't think cutting hours for a person who lives with a consumer is the correct thing to do. Basically when you live with your consumer you work beyond hours you're paid... caregivers who lives with their consumers should be reimbursed for that.”
- “In home care services are very important, because thus makes the older person part of the family and makes them feel needed and gives them positive influence of happiness and fulfillment (although person with dementia not really registers it as a healthy individual does, but yet its the road to take for good).”
- “Home care aides, cooked meals delivered, help with transportation.”
- “Education on how the wellness of mind, body and spirit maintain independence and the ability to make choices on how and where they want to live.”
- “Better support for the family as in education and training, when they are caring for a loved one. Offer a better selection of courses for training that is detailed for the person your caring for.”
- “More subsidized and low income housing and less waiting list.”
- “In-Home services to assist with ADL's by state or private agencies. These agencies must provide on-going education for staff and homecare workers.”
- “In order for the elderly to remain in their homes or places of their choice they need to be provided with the correct amount of care hours that fits their personal needs.”
- “Meals on wheels, available transport to Dr. appointments and shopping. I would also like to see ADA go into these Senior Housing apartments and put in walk in showers. My client has a horrible time getting in and out of his tub and needs a walk-in shower badly.”
- “Personal care, respite care, access to transportation for medical, shopping and adult day care.”
- “Accessible communication for people who are deaf, hard of hearing, and deaf-blind.”

Q.2 What are the most needed programs and services that allow older persons to live where they want to live? TOTAL (Providers Only) = 119



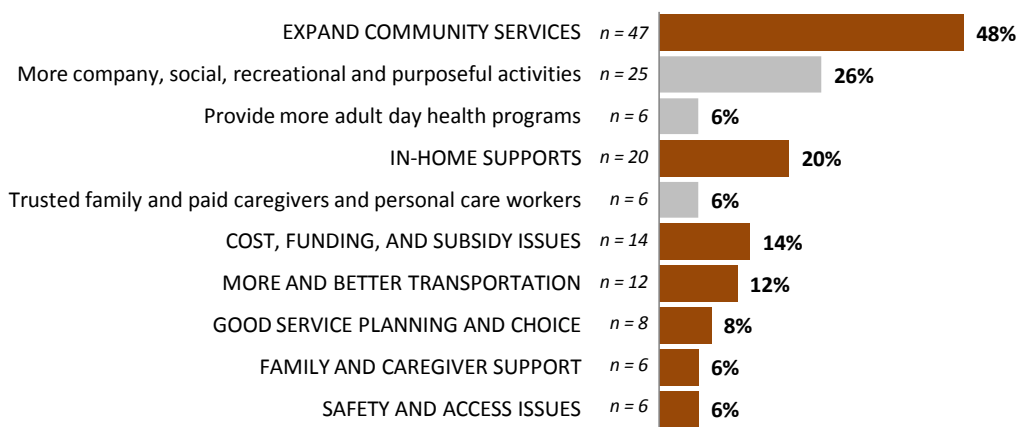
SOURCE: ALTSA Home and Community Services, July 2014.

Q.3 What other programs or services would you like to see for older persons and/or persons with disabilities?

98 service professionals answered this question. Community services (48%), in-home services (20%) and funding issues (14%) were the strongest emphases in their answers.

- “Extensive 1:1 companionship services, whether it be implemented by caregivers, or some type of youth volunteer/mentorship program that gives elderly persons a chance to pass on their knowledge and life lessons to the next generation and feel a sense of community as well as a sense of contribution to their society.”
- “I think Meals on Wheels needs some financial support and perhaps to expand for a growing population of seniors. The C.A.P organization needs some financial assistance too.”
- “Better mental health services. Counseling that specializes in the transition into aging and loss.”
- “Companionship programs...so many of the elders are lonely.”
- “Either allow funding for both Adult Family Home services and Adult Day Services or require Adult Family Homes to provide activity programs such as those offered in Adult Day programs.”
- “Social programs where people with disabilities can feel like they are part of the community. Adult day health programs and adult day centers.”
- “Mental health programs and community outreach for home bound seniors.”
- “Expansion of In-Home Services to include time for "Stress Reduction" activities which might include short car trips to outdoor activities.”
- “Day center programs, ability to communicate with others in similar situations. Support groups, info sharing, etc.”
- “More social programs geared towards certain ethnic groups. For senior immigrants it is very important to connect with others from the same ethnic group—to speak in their native tongue.”
- “A place for them to "go shopping" for free to get needed clothing, household supplies and toiletries. People on low incomes cannot afford to buy clothing since their food stamps have now been cut to 85 dollars a month.”
- “Help in their homes, with personal care, house chores, errands, and with meals. Things that let seniors stay in their homes, where they are more comfortable.”
- “Personally I wouldn't let my mother to be taken into a nursing home. She wouldn't be able to communicate with the rest of the residents and even the best staff wouldn't be able to 'figure out' her needs on time and in 'proper manner' in accordance with her upbringing and religious beliefs. And the latter will greatly affect her emotional standing.”

Q.3 What other programs or services would you like to see for older persons and/or persons with disabilities? TOTAL (Providers Only) = 98



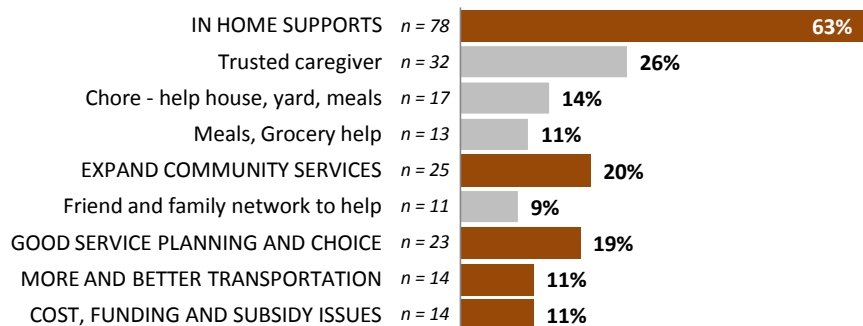
SOURCE: AL TSA Home and Community Services, July 2014.

Q.4 As you age, what do you think would be the most help in allowing you to remain in your own home?

123 service professionals answered this question. Almost two in three (63%) suggested in-home supports. Community supports (20%) and transportation (19%) were also frequently mentioned.

- “As long as there is someone to hire to take care of me then I will remain in my home until I pass away.”
- “In-home caregivers and chore workers that I could trust.”
- “A support system in place where I could remain home and not have everything pushed off onto one person.”
- “Health and services advisors to help me design a plan for aging in place. Someone like a financial advisor but for aging, perhaps an Aging Wellness Advisor program.”
- “Being treated with dignity and respect and being included in the decision making process within the confines of my mental state at the time the decision making is being done.”
- “Access to home care, education about aging and home safety.”
- “Having my house ADA accessible and some daily help when needed.”
- “In home aides and funding to cover their services, transportation, nursing services.”
- “I may in time need access to a ride to the doctors office, grocery store, or some other appointment.”
- “Affording the costs—everything is so high anymore. And getting around without little or no assistance.”
- “Transportation for food, clothing, banking, and recreation/physical exercise and a pleasant activity that reduces stress.”
- “Have my children on board early on and preparing our home so we are able to remain there as long as possible.”
- “Essential service information and professionals to check on me from time to time.”
- “Staying empowered to make my own choices.”
- “Physical and cognitive exercise.”
- “Ability and finances to take care of my needs and my home.”
- “Engagement in a community that is committed to addressing needs of all community members including older adults and individuals with dementia.”
- “Everything within my reach. Move my room downstairs, so I don't have to risk falling.”
- “In home care such as agency help. DSHS might consider paying other agencies that they do not cover now.”
- “Help with grooming, chores, medicine management, doctors appointments, transportation, grocery shopping, paying bills.”

Q.4 As you age, what do you think would be the most help in allowing you to remain in your own home? TOTAL = 123



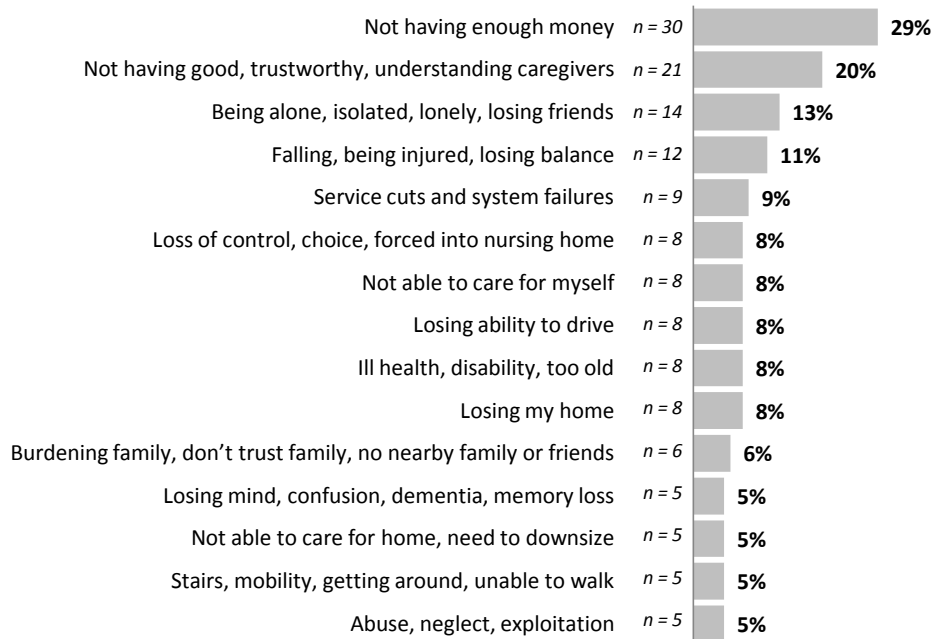
SOURCE: AL TSA Home and Community Services, July 2014.

Q.5 As you age, what is your greatest worry/fear as you think about staying independent and in your own home?

105 service providers answered this question. 29% worried about not having enough money. Other concerns were finding good caregivers, being isolated and alone, falling, inability to care for self and home, loss of independence, ill health, dementia, no trustworthy family nearby, losing their home, inability to walk, and not being found in an emergency.

- “Isolation from others due to not being able to get around on my own, communication struggles in regards to my hearing loss which can increase isolation, health issues and being treated poorly by people responsible to ensure my health and independence.”
- “My personal fear is I won’t be able to pay the taxes on the property that my family leaves to me—that thought terrifies me.”
- “The fact that if I require care, the worker/family member will not be paid fully and completely for the services/hours provided. There could be resentment issues to lack of pay and it could lead to abuse or neglect.”
- “Will I find someone who will care for me in the manner that I care for myself and other seniors?”
- “That I wouldn’t have enough help to stay in my own home. Loneliness.”
- “Falling. My mother-in-law fell in her home and instead of placing her in skilled nursing to get therapy so she could go back to her home my sister-in-law placed her in Assisted living where she waited for over a month for physical therapy. By then it was too late and she couldn’t walk on her own. She can only walk inside of her small apartment; otherwise she uses a wheel chair.”
- “I will not be able to afford the help, dealing with whatever physical ailment that I develop. Having honest people to assist.”
- “Ability to modify house so I can still safely live there; staying socially connected.”
- “Not being able to take care of myself, or losing mental capacity.”

Q.5 As you age, what is your greatest worry/fear as you think about staying independent and in your own home? TOTAL = 105



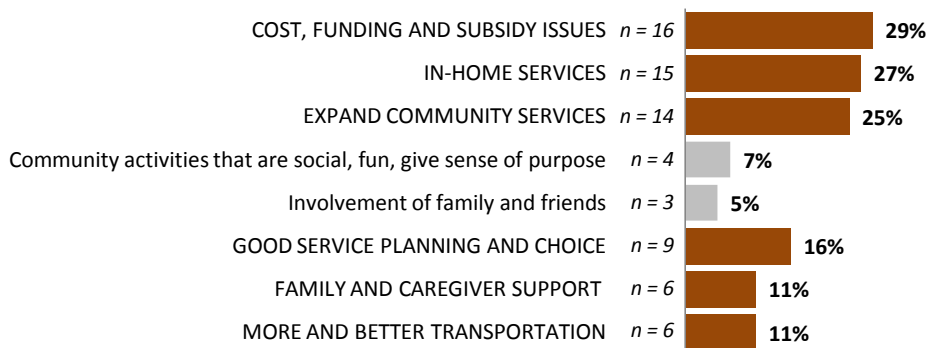
SOURCE: AL TSA Home and Community Services, July 2014.

Q.6 Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State

55 service providers answered this question. 29% discussed money issues, 27% discussed in-home services, and 25% discussed community services and supports.

- “People are aging in place. They want to remain independent. However, families are not necessarily around the block. People are reluctant to ask for help. Far too often situations are beyond the point of being reasonable for a person to be living independently. More resources and support are needed.”
- “Washington State spends a lot of time and money ensuring personal choice and personal liberties. I think that needs to be balanced. Fewer choices might be better choices—and more regulation might ensure more efficient services. For instance having housing with services— independent housing with in home services—but more flexible hours—so if one caregiver has 10 people in same apartment complex, efficiency is built in. Pay caregivers better—but hold them to a higher standard. Support case managers.”
- “The older people in our state need good transportation service, affordable in home care and affordable out of home care.”
- “The State of Washington DSHS generally does a good job of watching over the well being of senior citizens and those who need special care (younger people). Continue to expand those programs.”
- “Better wages, hours, health insurance for the in home care people. Keep caregivers healthy and being able to afford to stay home with family to care for them.”
- “Many adults don’t qualify for State services but cannot afford private services – yet need help in their home or everyday living situation.”
- “There must be more than 60 miles per month provided with caregiver for a person with disability.”
- “Keep the person in their own home as long as possible; nursing homes are too expensive and a person will get better care at home.”
- “Make sure the elderly receive the hours they need. I am a caregiver and some of my clients could use round the clock care.”
- “I think that older persons being taken care of by family members should be looked on by Aging and Long Term Care for their own protection. To make sure that they are not being taken advantage of by family members or even caregivers.”

Q.6 Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State. TOTAL (Providers Only) = 57



SOURCE: AL TSA Home and Community Services, July 2014

APPENDIX A

Supporting Tables

This table shows the number and percent of respondents in each group whose comments included each answer “category” or “theme.” For example, 92 people in the potential client group (17%) and 14 people in the professional-only group (14%) mentioned at least one in-home support in their answers to the first open-ended question.

If the answer was general – such as “in-home services” – then that response was included in the in-Home category but not included in any of the specific groups underneath. If the person mentioned specific community services (for example “help modifying home for access, a caregiver, and help with home maintenance”), then that answer was counted in the category total AND in all three of the subcategories. So the category total is an unduplicated count of the number of respondents mentioning one or more community services in their answer.

Q.1 If Washington State could improve services for people with memory loss/Alzheimer's/dementia, what would be the best first step to do so?

	Potential Clients and Family Caregivers TOTAL = 539		Aging and Disability Professionals Only TOTAL = 102	
	NUMBER	PERCENT	NUMBER	PERCENT
IN-HOME SUPPORTS	92	17%	14	14%
Safety and access changes to home	8	1%	1	1%
Personal care	12	2%	1	1%
Chore-type services	12	2%	0	0%
Trusted family or paid caregiver	40	7%	8	8%
Nourishing home meals	5	1%	1	1%
MORE AND BETTER TRANSPORTATION	2	0%	0	0%
ABUSE PROTECTION	3	1%	2	2%
FAMILY AND CAREGIVER SUPPORT	114	21%	21	21%
Respite	42	8%	5	5%
Involve family	14	3%	4	4%
Caregiver and family support	75	14%	16	16%
Support groups	6	1%	1	1%
GOOD SERVICE PLANNING AND CHOICE	72	13%	17	17%
Information and referral on services and medications	48	9%	17	17%
Include consumer in care planning	6	1%	1	1%
Better case management	19	4%	4	4%
Less red tape, easier access	19	4%	3	3%
COST, FUNDING, AND SUBSIDY ISSUES	103	19%	23	23%
More paid hours for caregivers	21	4%	5	5%
Housing subsidy	2	0%	0	0%
More funding for family caregivers	13	2%	1	1%
BETTER GROUP CARE OPTIONS	51	9%	13	13%
Get rid of bad facility	3	1%	1	1%
RESPECT, ACCESS AND RURAL AVAILABILITY	11	2%	1	1%
Treat people with respect and compassion	4	1%	1	1%
Extend services to rural areas	6	1%	0	0%
Serve underserved groups	3	1%	0	0%
EXPAND COMMUNITY SERVICES	103	19%	14	14%
Provide more adult day health programs	28	5%	7	7%
Apply well researched programs	9	2%	0	0%

Support earlier better screening and diagnosis	35	6%	4	4%
Improve medical care	19	4%	4	4%
Expand memory loss programs	11	2%	1	1%
Provide allied mental and behavioral health treatment	4	1%	0	0%
Apply best practices in prevention and treatment	9	2%	1	1%
Expand senior center role	1	0%	0	0%
Provide social and recreational activities	2	0%	0	0%
Treat hearing loss	3	1%	0	0%
INVEST IN EDUCATION AND INFORMATION	188	35%	47	46%
Education to reduce stigma	8	1%	8	8%
Education for person, caregivers and family members	105	19%	24	24%
Ongoing education for health and social service providers	43	8%	9	9%
Education for public	30	6%	9	9%
Education in general	39	7%	9	9%
BETTER QUALITY ASSURANCE	9	2%	2	2%
NEW STATE PLAN	26	5%	3	3%
New big plan to deal with aging boomers with dementia	13	2%	3	3%
Ask families what is needed	10	2%	1	1%
Establish the number in need	6	1%	0	0%
Reach out to likely need groups	4	1%	0	0%
OTHER	10	2%	3	3%

Q.2 What are the most needed programs and services that allow older persons to live where they want to live?

	Potential Clients and Family Caregivers <i>TOTAL = 668</i>		Aging and Disability Professionals Only <i>TOTAL = 119</i>	
	NUMBER	PERCENT	NUMBER	PERCENT
SAFETY AND ACCESS ISSUES	37	6%	7	6%
Communication and safety technology (cell phone, lifeline)	10	1%	2	2%
Safety and access changes to home	27	4%	5	4%
IN-HOME SUPPORTS	420	63%	83	70%
Safety and access changes to home	27	4%	5	4%
In home medical, mental health and case manager visits	32	5%	3	3%
Personal care	106	16%	20	17%
Chore-type services	85	13%	7	6%
Trusted family or paid caregiver	134	20%	27	23%
Nourishing home meals	67	10%	12	10%
MORE AND BETTER TRANSPORTATION	146	22%	21	18%
ABUSE PROTECTION	4	1%	1	1%
FAMILY AND CAREGIVER SUPPORT	86	13%	14	12%
Respite	57	9%	9	8%
Caregiver and family support	29	4%	4	3%
Caregiver education	18	3%	4	3%
GOOD SERVICE PLANNING AND CHOICE	87	13%	19	16%
Information and referral on services	23	3%	4	3%
Flexible case management, an advocate, HCS	42	6%	11	9%
Independent living support, choice	9	1%	4	3%
Good screening and assessment	9	1%	0	0%
COPES	28	4%	6	5%

COST, FUNDING, AND SUBSIDY ISSUES	113	17%	15	13%
Living wage for care giver	8	1%	0	0%
More care hours	14	2%	3	3%
Reduce cost to seniors	17	3%	1	1%
Funds or insurance to help pay for needed services	25	4%	4	3%
Grant for low income	5	1%	0	0%
Subsidy and program for middle income families	4	1%	0	0%
Housing cost help	15	2%	3	3%
Affordable senior housing close to services, transportation	26	4%	3	3%
BETTER GROUP CARE OPTIONS	31	5%	6	5%
Affordable and short term care	5	1%	3	3%
Deaf and deaf-blind group care	3	0%	0	0%
Dementia care	4	1%	0	0%
RESPECT, ACCESS AND RURAL AVAILABILITY	12	2%	2	2%
Provide service without discrimination, with respect	4	1%	1	1%
Fill rural and small community needs	2	0%	0	0%
Provide services in home language, including ASL	5	1%	1	1%
Services to gay and lesbian community – with partners	1	0%	0	0%
EXPAND COMMUNITY SERVICES	131	20%	25	21%
Provide more adult day health programs	21	3%	7	6%
More company, social, recreational and purposeful activities	30	4%	5	4%
Healthy group meals	21	3%	2	2%
Health and wellness exercise	9	1%	4	3%
Meal planning and preparation classes	17	3%	6	5%
Legal services	4	1%	1	1%
Handle pet care, include pets	3	0%	0	0%
Improve medical care	16	2%	2	2%
Improve mental and behavioral health access and service	6	1%	1	1%
Shopping help	14	2%	2	2%
OTHER	20	3%	0	0%

Q.3 What other programs or services would you like to see for older persons and/or persons with disabilities?

	Potential Clients and Family Caregivers <i>TOTAL = 512</i>		Aging and Disability Professionals Only <i>TOTAL = 98</i>	
	NUMBER	PERCENT	NUMBER	PERCENT
SAFETY AND ACCESS ISSUES	26	5%	6	6%
Communication and safety technology (cell phone, lifeline)	14	3%	3	3%
Safety and access changes to home	10	2%	4	4%
IN-HOME SUPPORTS	112	22%	20	20%
Safety and access changes to home	10	2%	4	4%
In home medical, mental health and case manager visits	11	2%	1	1%
Trusted family or paid caregiver or personal care	33	6%	6	6%
Chore-type services	24	5%	5	5%
Home monitoring and checkup	9	2%	1	1%
Nourishing home meals	17	3%	4	4%
MORE AND BETTER TRANSPORTATION	74	14%	12	12%
ABUSE PROTECTION	6	1%	0	0%
FAMILY AND CAREGIVER SUPPORT	56	11%	6	6%
Respite	34	7%	1	1%
Caregiver and family support	13	3%	3	3%

Caregiver education	15	3%	2	2%
GOOD SERVICE PLANNING AND CHOICE	78	15%	8	8%
Information and referral on services	34	7%	1	1%
Flexible case management, an advocate, HCS	46	9%	6	6%
Independent living support, choice	17	3%	1	1%
COST, FUNDING, AND SUBSIDY ISSUES	61	12%	14	14%
Living wage for care giver	3	1%	0	0%
More care hours	11	2%	7	7%
Medications covered, get rid of donut hole	6	1%	1	1%
Reduce costs to seniors and persons with disabilities	4	1%	1	1%
Funds or insurance to help pay for needed services	5	1%	4	4%
Grant for low income	3	1%	0	0%
Subsidy and program for middle income families	1	0%	1	1%
Housing cost help	7	1%	1	1%
Affordable senior housing close to services, transportation	4	1%	1	1%
Affordable housing for seniors, persons with disabilities	6	1%	2	2%
BETTER GROUP CARE OPTIONS	16	3%	3	3%
Affordable and short term care	3	1%	0	0%
Dementia care	2	0%	0	0%
NO NURSING HOME	1	0%	1	1%
RESPECT, ACCESS AND CULTURAL COMPETENCE	20	4%	4	4%
Provide service without discrimination, with respect	4	1%	0	0%
Inclusion for disabled adults	1	0%	1	1%
DD care centers	3	1%	0	0%
Autism-specific services	1	0%	0	0%
Services to person who are deaf and have low vision	7	1%	2	2%
Provide in own language, cultural competence and ASL	7	1%	2	2%
EXTEND SERVICES TO RURAL AREAS, EAST SIDE	6	1%	0	0%
EXPAND COMMUNITY SERVICES	240	47%	47	48%
Provide more adult day health programs	28	5%	6	6%
One-on-one companionship, visiting	25	5%	5	5%
More company, social, recreational and purposeful activities	114	22%	25	26%
Education, pre-planning, earlier diagnoses	10	2%	3	3%
Healthy group meals	11	2%	1	1%
Health and wellness exercise	31	6%	4	4%
Job support	16	3%	0	0%
Meal planning and preparation classes	9	2%	0	0%
Improve medical care	16	3%	3	3%
Improve dental, vision care, hearing support	12	2%	3	3%
Improve mental and behavioral health access and service	14	3%	2	2%
Provide all-ages, all-group services	7	1%	2	2%
Provide outdoor outings	11	2%	5	5%
Expand senior centers	11	2%	2	2%
Handle pet care, include pets	8	2%	0	0%
Improve volunteer organization	9	2%	4	4%
OTHER	12	2%	0	0%

Q.4 As you age, what do you think would be the most help in allowing you to remain in your own home?

	Potential Clients and Family Caregivers TOTAL = 609		Aging and Disability Professionals Only TOTAL = 123	
	NUMBER	PERCENT	NUMBER	PERCENT
IN HOME SUPPORTS	421	69%	78	63%
Safety and access changes to home – or downsizing	65	11%	8	7%
Chore-type services	134	22%	17	14%
Trusted family or paid caregiver or personal care	135	22%	32	26%
In home medical, mental health and case manager visits	23	4%	3	2%
Nourishing home meals	58	10%	13	11%
MORE AND BETTER TRANSPORTATION	98	16%	14	11%
FAMILY AND CAREGIVER SUPPORT	33	5%	2	2%
Respite	20	3%	0	0%
Caregiver and family support	14	2%	2	2%
GOOD SERVICE PLANNING AND CHOICE	102	17%	23	19%
Independent living support, choice	41	7%	9	7%
Flexible case management, an advocate, HCS, COPEs	49	8%	9	7%
Gov failure-Social Security gone, red tape, funding cuts	30	5%	7	6%
COST, FUNDING, AND SUBSIDY ISSUES	98	16%	14	11%
NO NURSING HOMES	3	0%	2	2%
EXPAND COMMUNITY SERVICES	143	23%	25	20%
Provide more adult day health programs	5	1%	2	2%
More company, social, recreational and purposeful activities	22	4%	2	2%
Education on aging, care, prevention and services	19	3%	4	3%
Friend and family network – supportive community	42	7%	11	9%
Help with financial planning, budgeting and paying bills	3	0%	0	0%
Improve medical care, better managing chronic problems	21	3%	1	1%
Improve mental and behavioral health access and service	2	0%	0	0%
Assist with mobility	4	1%	1	1%
Safety training and help	16	3%	3	2%
Keeping well	19	3%	6	5%
Eating healthy	13	2%	1	1%
Staying active	17	3%	3	2%
HOW TO CARE FOR DISABLED FAMILY IN HOME	1	0%	0	0%
OTHER	3	0%	0	0%

Q.5 As you age, what is your greatest worry/fear as you think about staying independent and in your own home?

	Potential Clients and Family Caregivers TOTAL = 692		Aging and Disability Professionals Only TOTAL = 105	
	NUMBER	PERCENT	NUMBER	PERCENT
Finances, ability to afford services, loss insurance, loss of job	180	26%	30	29%
Being alone, isolated, lonely, losing friends	98	14%	14	13%
Not having capable, trustworthy, understanding care when needed	89	13%	21	20%
Falling, injury, and balance	84	12%	12	11%
Need to downsize, not able to take care of home and yard	80	12%	5	5%
LOSS OF CONTROL, FORCED CHOICE, INTO NURSING HOME	65	9%	8	8%

Someone forcing me to leave my home, control my choices, no planning	21	3%	3	3%
Lack of control, losing independence, losing my freedom	27	4%	6	6%
Fear of nursing home	25	4%	0	0%
Not able to take care of myself	64	9%	8	8%
Inability to drive, not having transportation	61	9%	8	8%
Ill health, pain, disability, weakness, getting "too old"	59	9%	8	8%
Losing mind, confusion, Alzheimer's, dementia, memory loss	56	8%	5	5%
NO TRUSTED FAMILY CARE, DON'T WANT TO BURDEN THEM	47	7%	6	6%
Family who won't care, listen, or help – being put away	16	2%	1	1%
No nearby friends or family to help	18	3%	2	2%
Being a burden to children or caregiver, living with children	15	2%	2	2%
Losing my home	37	5%	8	8%
Not able to manage stairs, mobility, losing ability to walk and get around	35	5%	5	5%
Not being found after a major medical event or accident	34	5%	2	2%
Service cuts and system failures	29	4%	9	9%
Security and safety	25	4%	0	0%
No one to care for my pets	16	2%	0	0%
Not able to cook, not getting good nutrition	15	2%	1	1%
Not having an advocate to help with medical and case planning – legal rights	14	2%	0	0%
Being abused, neglected, or exploited	13	2%	5	5%
Who will care for family members I now care for?	10	1%	0	0%
Not enjoying life, not able to do what I love, no learning, no purpose, bored	10	1%	2	2%
Bad health care, not coordinated care, not enough health care	8	1%	3	3%
Depression, anxiety, other mental illness	7	1%	0	0%
Blindness, low vision, deafness, can't communicate	6	1%	1	1%
Homophobia, racism, cultural bias, meanness in system	3	0%	0	0%
Dying alone	3	0%	1	1%
Not able to pay for family care in home	2	0%	1	1%
Not staying close to family	2	0%	0	0%
I don't worry now	12	2%	6	6%
I don't have to be home	3	0%	0	0%
Other	5	1%	1	1%

Q.6 Please provide any other comments you may have regarding the needs and priorities of older persons in Washington State.

	Potential Clients and Family Caregivers <i>TOTAL = 343</i>		Aging and Disability Professionals Only <i>TOTAL = 55</i>	
	NUMBER	PERCENT	NUMBER	PERCENT
IN HOME SUPPORTS	49	14%	15	27%
Safety and access changes to home	0	0%	0	0%
Trusted family or paid caregiver or personal care	10	3%	1	2%
Chore-type services	5	1%	1	2%
In home medical, mental health and case manager visits	5	1%	2	4%
Not losing my home	15	4%	6	11%
Nourishing home meals	4	1%	3	5%

MORE AND BETTER TRANSPORTATION	15	4%	6	11%
ABUSE PROTECTION	14	4%	3	5%
FAMILY AND CAREGIVER SUPPORT	42	12%	6	11%
Respite	8	2%	0	0%
Caregiver and family support and education	16	5%	3	5%
Trustworthy caregivers	20	6%	3	5%
Pay family caregiver	11	3%	2	4%
GOOD SERVICE PLANNING AND CHOICE	53	15%	9	16%
Reduce red tape, ease access to services	12	3%	1	2%
Flexible case management, an advocate, legal, HCS, COPES	26	8%	4	7%
Independent living support, choice	20	6%	5	9%
COST, FUNDING, AND SUBSIDY ISSUES	95	28%	16	29%
More care hours	37	11%	5	9%
More dollars in senior services	26	8%	4	7%
Housing cost help	10	3%	1	2%
Funds or insurance to help pay for needed services	34	10%	8	15%
More help with food costs	5	1%	3	5%
More help with Medicaid and Medicare, more funding	6	2%	3	5%
BETTER TRAINING FOR LONG-TERM CARE STAFF	6	2%	2	4%
MORE REGULATORY OVERSIGHT AND MONITORING	11	3%	0	0%
BETTER GROUP CARE OPTIONS	24	7%	2	4%
Language and deaf cultural sense	2	1%	0	0%
Healthy food	1	0%	0	0%
NO NURSING HOME	19	6%	3	5%
TREAT ELDERS WITH DIGNITY, RESPECT, AND LISTEN TO THEM	24	7%	2	4%
CARE FOR HEARING LOSS	8	2%	0	0%
EXPAND SERVICES IN RURAL AREAS	6	2%	0	0%
EXPAND COMMUNITY SERVICES	97	28%	14	25%
Provide more adult day health programs	4	1%	2	4%
More company, social, recreational and purposeful activities	27	8%	4	7%
Friend and family network	18	5%	3	5%
New type of community, expand role of community	7	2%	1	2%
Eating healthy and stay active, gentle fitness	5	1%	0	0%
Improve medical care, better managing chronic problems	10	3%	2	4%
Improve mental and behavioral health access and service	9	3%	0	0%
Improve hearing, vision and dental care	12	3%	2	4%
Education on aging, chronic illness, advance planning	14	4%	0	0%
Improve access to hospice and end of life care	4	1%	0	0%
Increase access to job training and job support	6	2%	0	0%
Safety training and help	3	1%	0	0%
GOOD JOB WASHINGTON	13	4%	1	2%
THANK YOU FOR ASKING	5	1%	0	0%

RESPONDENTS WERE POTENTIAL CLIENTS, FAMILIES AND FORMAL/INFORMAL PROVIDERS

1,607 people answered at least one question in the survey. One in five (20% or 325) did not answer the “status” questions about being over 60, having a disabling health condition, knowing people needing care, or providing paid or unpaid services to people who are elders or disabled. Most of those people also did not answer the open-ended questions, but a few did.

This paper reports separately on open-ended question answers from two groups of respondents:

- All persons who were over 60 OR had disabilities OR were family caregivers (paid or unpaid). This group also includes a few people who did not answer the status questions or who were younger and not disabled – but were not professionally or personally involved in aging/disability services.
- The 223 persons without disabilities under the age of 60 who were paid aging and disability service providers but not for family members (the last row in the table below).

These groups were chosen because many of the respondents were simultaneously client, family caregivers, and providers. As the table below shows, about half (642) were potential clients—either over 60 or with a disability or both. However, two-thirds of those potential clients (464) were also providing paid or unpaid services to other elders or persons with disabilities—or knew family members or neighbors who needed care. So only 178 were “only” potential clients.

Similarly, 749 people were providing paid services to elders or persons with disabilities. But only 510 were under 60 and not with disabilities—and 287 of those 510 were serving persons in their family, paid or unpaid. So only 223 people were “only” paid providers of care.

KNOWN STATUS OF RESPONDENTS TOTAL = 1,283	NUMBER	PERCENT
ALL POTENTIAL CLIENTS (Over 60 and/or with Disability)	642	50%
Potential clients also providing paid and unpaid services to family	464	36%
Respondents who are ONLY potential clients	178	14%
ALL PAID CARE PROVIDERS	749	58%
ALL PAID CARE PROVIDERS WHO ARE NOT POTENTIAL CLIENTS	510	40%
Paid providers not potential clients serving family members (paid or unpaid)	287	22%
Respondents who are ONLY paid Providers	223	17%

METHOD: CONTENT ANALYSIS—Content analysis is the creation of categories for grouping answers to open-ended questions. For this paper, blank or unresponsive answers (e.g. “na” and “don’t know”) were not counted as “informative” answers. The informative answers were categorized into topics—at first quite detailed, and later more general. A single answer might address several topics; if so, it was included under each of them.

About half of the respondents answered the open-ended questions. The number of answers to each question is included in the findings.

For five questions many of the broader answer categories were similar—categories included In-Home Supports, Money Issues, Community Services, Care-giver and Family Support, Group Care, Transportation, Good Service Planning and Choice, Safety and Access, Abuse, Quality Monitoring, Access and Respect or Dignity.

For Question 1 (which asked about first steps regarding care for persons with dementia) extra categories were added: Education, and State Plan.

For Question 5 (which asked about fears rather than services) the categories were different: Money, Isolation, Poor Caregiving, Falling, Inability to Care for Home or Self, Loss of Independence, Inability to Drive, Ill health, Dementia, Family, Losing home, Losing Mobility, Not Found after Accident or Event.

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Copies of this paper may be obtained at www.dshs.wa.gov/rda/
 or by calling DSHS’ Research and Data Analysis Division at 360.902.0701.
 Please request REPORT NUMBER 8.32



What Do Older Adults and People with Disabilities Need?

Answers to Open-Ended Questions from DSHS' Aging and Long-Term Support Administration State Plan on Aging Survey

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RDA Research & Data
Analysis Division