

PORTLAND, OREGON METROPOLITAN AREA



Spring 2009

It Takes a Village to Live a Life
A Community Assessment on Aging

PRESENTED BY

UNITED WAY OF THE COLUMBIA-WILLAMETTE
VOLUNTEERS OF AMERICA-OREGON
THE URBAN LEAGUE OF PORTLAND
LIFEWORCS NW



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Acknowledgements

This report presents the findings from a 2009 Needs Assessment and Gap Analysis on issues of importance to Portland Metro area caregivers and older adults. A leadership team representing the United Way of the Columbia-Willamette, Volunteers of America - Oregon, the Urban League of Portland and LifeWorks NW conducted the project. The following individuals donated many hours and valuable creative energy to this process. It is the expectation of those involved that this is a beginning – not a conclusion. The leadership team is committed to formulating a strategy to implement the concepts and visions set forth in this report.

STEERING COMMITTEE AND PROJECT TEAM

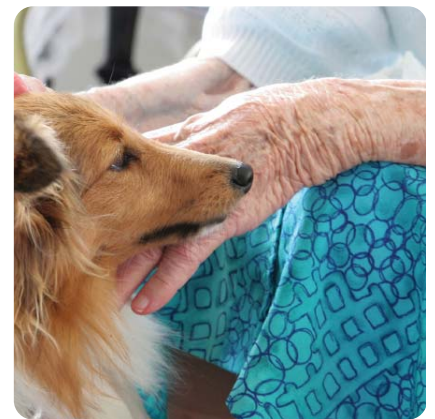
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The following senior and caregiver specialists contributed their expertise to this important discussion on how our region can be best prepared to meet the needs of older adults and family caregivers. Their input helped identify creative solutions for additional programs to serve the growing population of older adults in the Portland Metro area.

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Background & Information

A healthy community is one where an individual can **both grow up and grow old**. By 2030, nearly one in five Portland area residents will be over the age of 60. Services available to help them age in place not only contributes to their quality of life, but also significantly impacts the local and state economy. Vibrant, healthy and active older adults bring a wealth of resources to the community. They invest, play, support arts and culture, community events and schools and pay taxes. It is clearly in the best interests of society to support them and invest in services that allow them to live independently for as long as possible. This is important on a number of levels: income security, dignity and quality of life, connections to social networks, having purpose in life and the safety and comfort of living in one's own home and community.



While there are many factors that contribute to older adult independence, our research indicates that family caregivers are often the primary reason they are able to remain in their own home. For those older adults that do not have family living near-by, access to paid caregivers or in-home services such as Oregon Project Independence is critical. Therefore, one of the primary foci of this assessment is to address the unmet needs of these caregivers and attempt to steer public resources and provide policy advocacy to support them.

This report will highlight results from older adult surveys conducted within the past two years; present findings from our Spring 2009 Caregiver Needs Assessment Survey; offer creative suggestions for new programs and solutions to address common needs for both older adults and their caregivers;

develop a framework for public policy advocacy on key issues; and offer a listing of "Best Practices" in the field to demonstrate some of the activity taking place nationally and internationally.

Specific objectives of this process were to identify unmet needs of older adults and their caregivers in the Portland Metropolitan area. The most significant gap in information appeared to be about the process that caregivers go through to provide care without having to make decisions under high emotional stress while in a crisis situation. Research was gathered from professionals in the field, older adults, caregivers, and review of existing data and best practices – nationally and internationally. Existing data review indicated limited research has been conducted to determine needs of family caregivers, which became the primary focus for generation of new research data.

The information in this report will be used to guide strategic planning within the collaborating agencies and identify areas that need advocacy and public policy attention. The steering committee started this project with the hope that the final report would frame the positive aspects of a growing senior community and adopted the following vision and goals statement to set the tone for the over-all planning process.

VISION STATEMENT

The greater Portland Metropolitan region will gain national prominence as a place where elders are viewed as a valuable **community treasure**. Their talents and resources will be tapped to enrich a multigenerational community. People living here will be able to grow old with dignity in an environment of support and nurturing.

This vision will be accomplished through:

- Assuring that services and consumer choice will be available regardless of the ability of individuals to fully pay for their services.
 - Promotion of both individual responsibility and community support.
 - City and county residential and other zoning changes that will support the unique needs of older adults – transportation, shared housing, supportive infrastructure, etc.
 - Communities and residential areas that support and provide services for people over 60.
 - Community champions dedicated to advancing a public policy agenda that supports aging in place.
 - The continued development of a continuum of housing and services that will help people to thrive and provide care for them when and where they need it.
 - Support to family and other community caregivers and to communities in order to be able to plan for, advocate for and support their elders.
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With increased life expectancy, more and more people can expect to spend many years of their life as “seniors”. **Most societies have not yet planned for either the needs of its increasing number of seniors or the gifts of time, perspective and expertise they can provide. Building the necessary infrastructure to best support seniors in their needs as well as the infrastructure that enables them to best utilize their strengths is an urgent community need.** It is our goal to address innovative projects that will support building this infrastructure and contribute to lifelong vibrancy of seniors living in our region.

“Too few communities have developed concrete plans to address the problems associated with the aging Baby Boomer generation. Even fewer have prepared themselves to capture the significant potential benefits that will result from this unprecedented pool of talent and experience. Only communities that plan well will reap these benefits.”¹

— Ted Wheeler, Multnomah County Chair

¹ Multnomah County’s Everyone Matters: A Practical Guide to Building a Community for All Ages

It is our expectation that the recommendations in this document will plant the seeds to develop programs and services that cannot or should not rest on the shoulders of a single agency. The innovations, opportunities and contributions that partnerships among governments, non-profits and private enterprises can foster must be channeled through a network of organizational inter-connectivity. In this way, we will improve the lives of all residents and define as champions the community leaders who make it happen. How this region treats its older adults will define a thriving community or one that withers; this is our challenge as we move through the twenty-first century.

The report is a **“Call to Action”** to the community, service providers, the private sector, and local and state government to begin a long-range economic development strategy that factors in the return on investment from increasing services to support Oregon’s aging population and the people who care for them.



Chapter I: **What We Know**

CHAPTER 1: WHAT WE KNOW

This chapter offers an analysis of existing research. The following recent surveys and assessments were reviewed to determine characteristics, concerns, strengths and needs common to the over 60 population in the Portland Metropolitan area:

- Multnomah County/PSU Senior Needs Assessment – 2008
 - NW Portland Ministries (NWPM) Senior Survey – 2008
 - 2007 Family Caregiver Support Program Study – Multnomah County
 - 2007 American Community Survey – Multnomah County Aging and Disability Services
 - Everyone Matters: A practical Guide to Building a Community for All Ages – Multnomah County Task Force on Vital Aging – 2008
 - United Way of the Columbia-Willamette Community Needs Assessment 2007-2008
 - The World Health Organization’s Age-Friendly Cities Project in Portland, Oregon – 2006-2007
 - Multnomah Aging and Disability Services 2007 Strategic Planning process
 - National Council on Aging: Survey of Innovative Health and Supportive Services in the Aging Network – 2000-2001
 - Investor Protection and Trust: A Survey of Oregon Adults Ages 40 and older – AARP - 2008
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DEMOGRAPHICS AND DATA OF SIGNIFICANCE TO THIS PLANNING PROCES

The U.S. Census Bureau estimated that between 2005 and 2007², 10.4 percent of the population of Portland was aged 65 or older (approximately 56,418 people), compared with 12.9 percent of Oregon, and 12.5 percent of the United States. However, the baby boom cohort (i.e., those born from 1946-1964) will begin turning 65 in 2011, which will substantially contribute to a dramatic rise in both the absolute number and proportion of older adults. Population projections for Oregon provide an example of the type growth that can be expected in Portland; from 2010 to 2030, the state will see an increase in the proportion of those 65 and older from 13.0 percent (494,328 people) to 18.2 percent (881,957 people)³.

According to the National Adult Day Services Association, nearly one out of every four US Households today – 22.4 million – provides care to a relative or friend aged 50 or older. Caregivers contribute billions of dollars to society in the form of unpaid work.

More than 109,000 seniors age 65 and older live in the Portland region. Nearly 26,000 of these are 85 years and older. As Baby Boomers begin to retire, the need for planning to support increasing numbers of seniors becomes even more critical. Seniors from minority groups make up an increasing number of seniors in need of services. 90% of seniors prefer to live in their own home as they grow older. With appropriate supports, they can continue to do so and at a much lower cost than in a nursing home. No matter where seniors choose to live, they need the assurance that they will receive quality care and the supports for community living they need.

Unpaid care from family, friends or neighbors is the main source of help for most older people living in the community. Nearly one out of every four households provides at-home care to a person aged 50 or older.

² U.S. Census Bureau, 2005-2007 American Community Survey 3-Year Estimates, 2008

³ U.S. Census Bureau, Population Division, Interim State Population Projections, 2005.

Over 50% of these primary caregivers are employed full-time and the vast majority are women.⁴

ECONOMIC IMPACTS

The burden of employee caregiving is costly to business. The estimated annual cost of lost productivity is between \$11.4 and \$29 billion for U.S. businesses. Caregiving costs businesses when employees have to miss or interrupt their work due to an eldercare crisis. Some employees may ultimately choose to quit to meet their caregiving responsibilities. More than 14 million caregivers balance work with caregiving roles.

The duties of caregiving can have a direct impact on work productivity. Employed caregivers may need to alter their work schedules to come in late, leave early, take long lunches, make or receive phone calls at work, or otherwise deal with sudden caregiving-related crises.

In a study of 305 employed caregivers of the elderly, conducted by the Institute on Aging and the Older Women's League; hour-long, face-to-face interviews revealed that almost a quarter of the respondents changed their employment situations drastically as a result of their elder care responsibilities, including changing jobs, becoming unemployed, becoming self-employed, or taking on several part-time jobs. Only 10% did not experience negative effects on their ability to work in the same way they did before assuming elder care responsibilities. Respondents are most likely to have talked about their elder relatives while at work (56%), to use the telephone more than usual (48%), and to rearrange their work hours (45%). About a third arrived late or left work early because of elder care responsibilities (37%), were absent (30%) or were distracted at work (37%) because of elder care.

Our country will see a 44% increase in individuals with Alzheimer's disease by 2025, with the Western and South-eastern states to be hit the hardest. **Oregon will experience a 93% increase.** According to US Census data, the size of the older population (65 and older) will double over the next 25 years, growing to 70 million by 2030.⁵ The business costs for workers who are caregivers of people with Alzheimer's disease alone escalated from over \$26 billion in 1998 to over \$36 billion in 2002.⁶

ELDER CARE TRENDS

The American family is undergoing historic changes. Because of an unprecedented demographic shift, we are changing from a young to an old society. This trend has been called the "age wave," and it is forcing critical changes in the way we live and work, and in how we care for those we love. One of the most dramatic changes is in the number of people who are responsible for elder care. A study by the American Society on Aging estimates that approximately 34 million Americans are now caring for a parent or older loved one. This number will grow exponentially as baby boomers reach retirement age. **By 2010, employees will care for more dependent elders than children.** As with childcare, the problems associated with elder care are largely the result of inadequacies in the social services available in the community. The complexity and duration of adult caregiving often increase stress levels, absenteeism and quit rates beyond those caused by childcare.

80% of all care provided to older people in our country is provided by family members. Over 60% of these caregivers work full or part time. More than 40% also care for children under 18. Caregivers dedicate an average of 18 hours per week to provide care for older persons and even more when the person has multiple disabilities. The aging population is growing, particularly those 85+, increasing elder care needs. The workforce is aging, increasing the number of caregivers in the workforce.

⁴ United Way of the Columbia-Willamette — 2007 Community Needs Assessment: <http://www.unitedway-pdx.org/work/CNA-report.html>

⁵ State-specific Projections through 2025 of Alzheimer Disease Prevalence — Neurology, May 11, 2006.

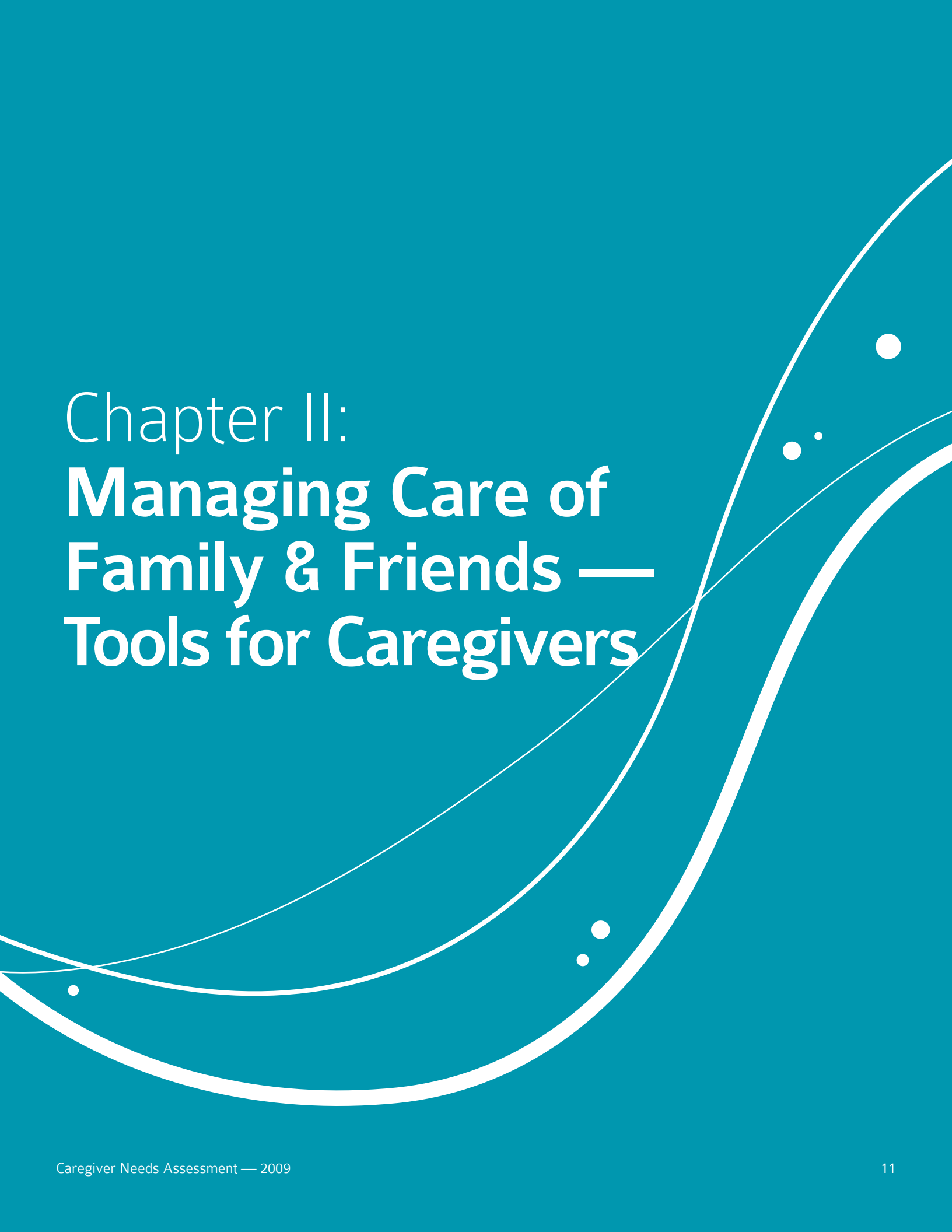
⁶ Alzheimer's Disease: The Cost to US Businesses in 2002.

⁷ National Association of Area Agencies on Aging: Business and Community Solutions for Employee Caregivers

Generation X and Generation Y are smaller in numbers than baby boomers, reducing the number of caregivers for the future. More and more workers are joining the sandwich and whopper generation (three generations) increasing caregiver obligations.⁷

DATA & TRENDS FROM LOCAL SURVEYS OF OLDER ADULTS

- The Multnomah County Aging Survey and NWPM surveys both found a few very positive indicators: A high percentage of responders indicate they walk every day, their level of physical activity is the second highest in the nation, with Colorado being in the number one spot; the majority have someone to call if they need help; once they reach the age of 65 and qualify for Medicare, they seem to be getting the medical care they need with a high percentage getting annual check-ups and immunizations; 61% reported their health to be good to excellent; and their nutrition rate appears to be high. These are excellent indicators that many area seniors will enjoy a vital aging process.
- A large percentage expressed need for housing maintenance help – small things to be done to keep up their households: small home repairs, weatherization, yard help, gutter cleaning, ramps/access support, bath aids/grab bars, etc. 11% listed needing help with one thing, 21% listed two things, and 15% mentioned six or more things.
- 86% of renters and 68% of homeowners spend over 30% of their income on housing costs. 85% indicated they want to stay in their homes, but over 24% were not confident that they would be able to. When asked if they would have to move within 5 years, 50% said yes in 1 to 5 years and another 40% said yes to 5 years. A high percentage of these responders were in the 55 to 64 year age group. Cost of housing, maintenance, change in family situation, need for repairs, and modifications were reasons given. 50% needed help with yard care.
- A high proportion of respondents in the NWPM report expressed needing supportive services and volunteer help that enables them to maintain their current levels of independence.
- 1/3 of those surveyed expressed concern about being able to evacuate in case of an emergency or disaster. Most did not know about the Voluntary Emergency Registry and only three had actually registered. Multnomah County expects to address this through more outreach.
- A significant number of responders to all surveys expressed frustration about lack of physicians and dentists with adequate training in geriatrics, lack of oversight of nursing and assisted living facilities, lack of insurance coverage for health-care related needs and thus lack of affordability of care, and poor quality of care.
- Continuation of in-home care services through Oregon Project Independence was a top priority in all surveys where this question was asked. Also, increased funding for family caregiver support was often cited as a critical need for consideration by the Oregon legislature.
- Significant gaps in service capacity included: transportation, food security, affordable housing, mental health services, and support for family caregivers.
- Services for seniors should be individualized, client-driven, and easy to access.



Chapter II:
**Managing Care of
Family & Friends —
Tools for Caregivers**

CHAPTER II: MANAGING CARE OF FAMILY & FRIENDS — TOOLS FOR CAREGIVERS

Caregiving may be divided into two categories, formal and informal. Formal caregivers are paid health care providers who assist people in their homes, assisted-living settings, and nursing facilities. Informal caregiving is provided by unpaid family members or friends. Family members are the primary and preferred caregivers, providing almost 80 percent of care to older adults. Care may include resources such as time, money, and/or shared living spaces, all of which support independent living. Family caregivers are the backbone of the long-term care system. The care they provide reduces demands on the health care system by preventing or delaying institutionalization or the need for more formal, paid caregiving services.

When seniors living in their own homes do not receive appropriate support services, they are more likely to have significant and costly health needs, and stand a greater chance of moving into a nursing home. Providing services within the community is preferred by seniors and is more cost effective. The typical cost of providing services to seniors living in their own homes is \$550 per month. The typical cost of care in a nursing home is \$5000 per month.⁸

74 caregivers responded to the 2009 Caregiver Needs Assessment Survey conducted by the project team. Respondents had the choice of completing the survey in an electronic, on-line survey or hard copy submitted by mail. 76% chose to submit electronically. The data goal of the survey was to determine specific issues and services that if in place would move a family from crisis to a thoughtful process of providing care to persons in the last decade of life. A secondary outcome was to detail recommendations for new services and resources to assist family and other caregivers with providing the best care in a non-crisis environment.

SIGNIFICANT RECOMMENDATIONS BASED ON SURVEY FINDINGS

You can find the complete survey results online at www.voao.org or www.unitedway-pdx.org

Unpaid family caregivers support over 84% of older adults and of these seniors, 73% are able to remain in their own homes and live somewhat independently due to this care. The cost to the public sector to provide this level of support would be enormous. Having a family caregiver able to assist with daily activities and household assistance is the single largest factor preventing these older adults from entering expensive residential care. From a policy perspective, family caregivers need and deserve public support. It is obvious from this survey that they currently get very little support – and the weight of being solely responsible for the care of an older person is taking a toll. Many expressed symptoms of depression and being overwhelmed with the responsibility.

“I knew that this was going to be a difficult experience, but if I had truly realized to what degree this would impact my life, I might have gone a different route. Caregiving has its ups & downs, but realize that in our society, it is an unpaid, thankless profession. I feel very sorry for the millions of ordinary Americans like myself, who have yet to experience this situation. I don’t envy them in the least bit. I wouldn’t even wish this on my worst enemy!”

⁸ United Way of the Columbia-Willamette — 2007 Community Needs Assessment: <http://www.unitedway-pdx.org/work/CNA-report.html>

Survey responses generated the following suggestions and recommendations for system improvements:

- The medical community should implement a care coordination or multi-disciplinary model of care that incorporates all members of the care team. They need to meet together and share information about the older adult in their mutual care. Over-all, medical professionals need more geriatric training and/or awareness of how to connect their patients to expertise in the field.
- Establish a One-Stop Senior Resource Center to access information and resources. The center should be a clearing-house for data and services and include on-site support from professionals. People could ask questions and get results at one location, instead of accessing information in many different areas where they often get confusing results on what to do next. The lack of both time and money was also a common response to their ability to access needed services. The 2-1-1 resource is a beginning, but not one survey responder indicated they had used it. That service clearly needs to be better communicated to the caregiver community.

“I have said repeatedly throughout this survey how wonderful it would be to have one ‘one-stop shopping’ center I could go to that had all the experts or consultants under one roof, so to speak. They could assess our situation, make recommendations, place a few phone calls, and advocate for her. I would have been willing to pay a fee for this service. These would be people who are experts in their fields. You might only deal with one or two front persons or ombudsmen who conferred with other specialists and who were knowledgeable of local, state and federal resources available to meet my mom’s criteria. This could be huge in light of a burgeoning baby boom population lumbering into their old age, and could even go nationwide.”

- Education and awareness on the aspects of progressive debilitating diseases would be highly valued by caregivers. Understanding what the older person will experience as these diseases progress would help avoid making decisions in a crisis situation. Area hospitals, AARP, and associations for specific diseases could orchestrate a coordinated approach to provide this on-going education.
- More respite help is clearly the single largest supportive resource needed by caregivers. Most survey respondents mentioned how valuable it would be to have some time off from their daily care obligations. Perhaps a group of social service providers could jointly organize an army of trained volunteers to provide this support. A full time volunteer coordinator would be needed to support the program. Caregivers would have a one-stop location or phone call to tap into this assistance. The Multnomah County Vital Aging Task Force report offers many valuable tips to engage the newly retired baby boomers in volunteer activity. This would be one area where these volunteers could make a huge impact!

“Community service or volunteering through nonprofit and charitable organizations is a very common pursuit in the US and contributes significantly to our overall quality of life here in Multnomah County and throughout our state. The nonprofit sector has many reasons to care about our aging population, particularly given its size, educational and skill level, good health and relative wealth. The boomers will have the money, expertise, desire and time to engage in community work through nonprofit organizations. The Portland metro region ranks number six in the county for volunteer rates of civic engagement.”⁹

“With the recession throwing more than 6 million Americans out of work and bringing hard times to millions more, the need for help is great and growing. But charities across the country report that fresh recruits – employed and un-employed – are knocking on their doors in record numbers, ready to serve. Four years ago at New York Cares the group had 27,000 volunteers. This year it anticipates over 50,000. Taproot in San Francisco saw its volunteers increase by 122% last year – even though it stopped actively recruiting. Without more money to train and manage the surge of volunteers, this will be a missed opportunity for charities. This is a make-or-break time. We need to channel and leverage this great volunteer response.”¹⁰

⁹ Everyone Matters: A Practical Guide to Building a Community for All Ages — 2008

¹⁰ Brother Can I Lend You a Hand — AARP Bulletin June 2009



Chapter III: **Creative Concepts & Solutions**

CHAPTER III: CREATIVE CONCEPTS & SOLUTIONS

A group of 20 area specialists in the field of aging services engaged in a facilitated think tank process on October 29, 2008. The over-arching goal of the discussion group was to tap into this expertise and creative energy to identify a few specific big-picture project concepts that would have high impact, mobilize systemic support from agencies offering services to this population, have potential for National significance, and create a vehicle to secure new funds and resources.

The following project concepts emerged as high priority solutions in the focus group as well as continuing discussions and data analysis throughout the nine-month planning process:

1 Housing Concept Idea: Aging in Community Zones – similar to an enterprise zone.

Provide incentives for people to move to communities that offer the most services for an aging population. The community will develop around a strong service center, develop hub and spoke services and targeted co-located services.

Community Features: Small units, “Boomer Centered” but still intergenerational, access to food and local harvest, access to social events and activities to reduce isolation, offer concierge services, and include adult foster homes. The community will become a magnet for supportive services, supplies, and businesses that cater to this demographic; therefore becoming an economic development tool as well. It will offer employment opportunities for youth and older seniors. Possibly tie in with affordable housing funds and TIF – incentives to live in the zone.

2 Transportation: Inventory/assessment of need.

Co-location of seniors in an Aging Community Zone will reduce transportation needs and help solve the transportation burden. It will also allow for more use of small energy efficient units like pedi-cabs or electric carts/vehicles. Pattern this after the Urban League transportation system model. Include a review/inventory of seniors and develop research to build a model and get the word out.

Benefits: Stimulates social interaction, provides access to services, is a 24-hour resource, uses ride connection vehicles, coordinate Red Cross “Lift”; coordinate with drivers and vans used in senior centers and assisted living facilities in order to maximize use of these resources in the community.

3 Host an International Day of Aging — done jointly with all system partners.

4 Connections2Care Project – Create a non-profit or private entity whose charge will be:

Facilitate the integration of services; increase access to services; motivate individuals to use these services.

Project components:

- Caregiver education – the caregivers in the home also will benefit from this project
- “Consolidation of Care” Bring together service providers; engage in a community conversation or dialogue; “Any Door is the Right Door” to connect to someone that can assist with access to service
- Media and outreach – use Public Service Announcements, have a media plan, have people able to go into homes to discuss services
- Work with the totally isolated. Help them get to medical appointments, shopping, emergency services
- Master database and clearing house for best practices, ideas, staff development, etc.
- Talk about aging. Advocacy. Invest in a full year conversation on “What are Old People For?”

5 Living Well with Chronic Illness Project

Project elements:

- Create a systemic approach to Chronic Care management – Diabetes, Arthritis, Depression/dementia
 - Incorporate a fitness plan
 - Conduct a long-range study on use of medications, caregiver support and buy-in to reduce reliance on medications and encourage more fitness
 - Use an intergeneration model to get kids involved
 - Utilize the district centers and existing resources to assist with triage and individual care plan
 - Incorporate a follow-up tracking process
 - Create an on-line forum – blog to track individual progress and provide incentives and motivation to stay on track
 - Help people understand how they can live well with chronic conditions
-

6 Service System realignment:

Use research and link higher education with policy makers and system leaders to assure evidence-based practice; guide system development and promote appropriate education for professionals, community and families.

Over-riding value:

The development of community wide planning that creates an integrated system of services promoting person-centered services, consumer choice, supports self-determination and individual responsibility and assures access to an integrated information system.

Specific Focal Points:

- Workforce Development
- Education of medical and social service staff/employees
- Family education
- Education of Employers
- Case management models
- Service providers and local governments focus on aging in one's community (not just at home) One should be able to grow up and grow old in their community
- Employers understand and can fully utilize an aging work force
- Information and Referral systems are well developed and easy to access
- Living options provide choices with dignity

Other points:

Re-orient support systems around person-centered care. Conduct outreach to physicians and specialists. Provide information about planning for long-term care. Educate employers about the realities and needs of their employees who provide primary care for an elder relative.

7 Volunteer networks:

A large majority of survey responders indicated a need for assistance with home repair and maintenance. Engage, train, mobilize student volunteers to do some of this work – leading to job skill development as well as filling a needed service gap. Expand the Habitat for Humanity model to include home repair work.

8 Trained Volunteer Support Team:

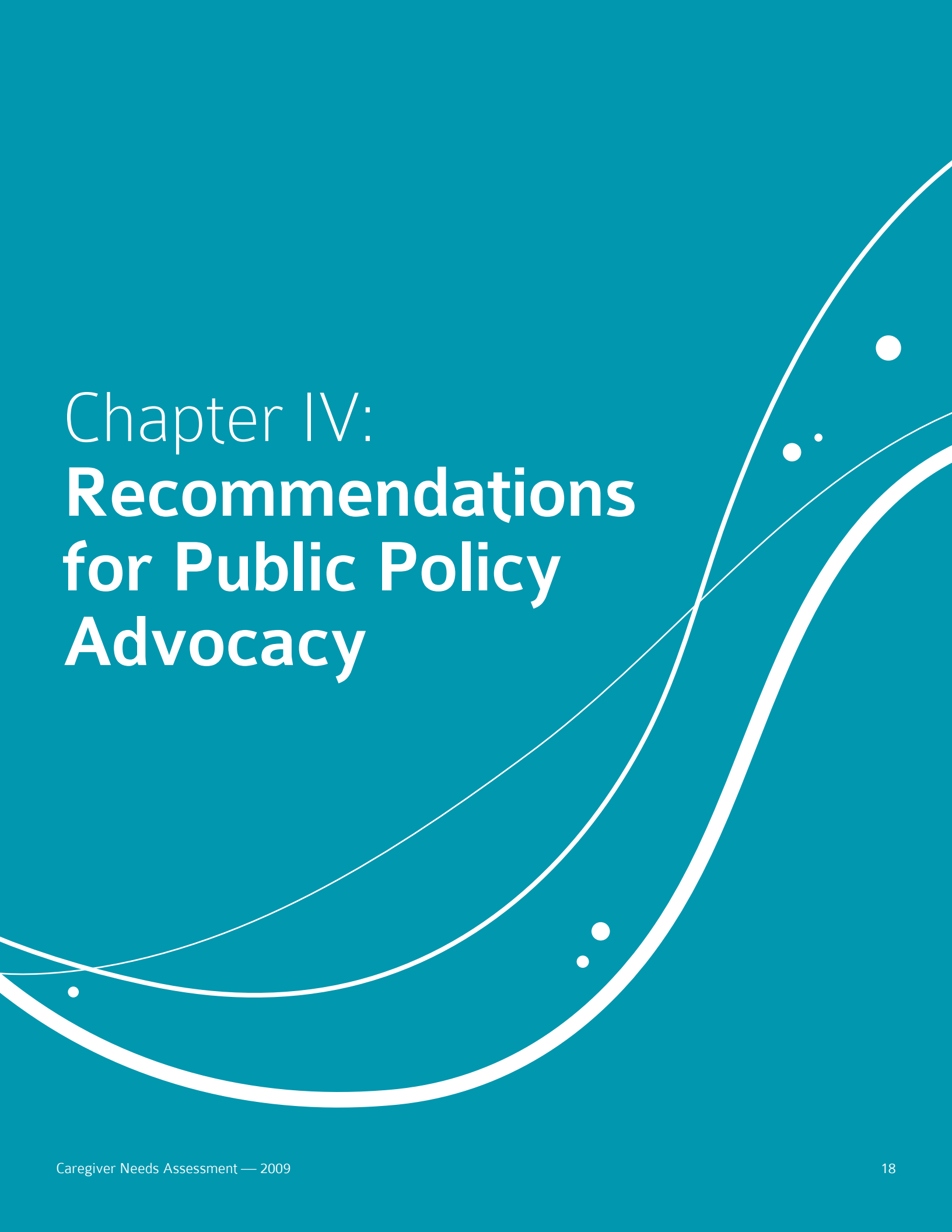
It seems with the crisis model there is a need to do many things at once that are more than the resources of one person. Perhaps we need folks like “sitters” in the hospice sense, trained volunteers to sit with the older adult giving the caregiver time to do some of the running, coordinating, synthesizing of information and then be able to use the sitter as a sounding board for progress, next steps etc. This may sound like respite care but I see it as different in that it is short term but buys time for the caregiver to multiply their resources and use the extra help to get more comfortably to the next level. It seems like more caregivers are in crisis mode than planning mode, maybe 80% crisis and 20% planning.

9 Community Dialogue:

We need a set of forums that gather folks together who are interested in the 20s, 30s, 40s, 50s, 60s (all ages, maybe capturing what we learned from the decade and capturing stories and insight into a product) current events forums like the future of the internet, creating sustainable communities, multigenerational and green living neighborhoods, intentional communities that nourish each members interest/hobbies, reducing our carbon footprint workgroup, building a strong economy etc. Coming together around issues that matter to all of us and highlight the contributions of elders.

10 Intergenerational Day Care:

Connect older adults with children in a day care environment. Many day care facilities are either using seniors as volunteers to assist with care for the children, or providing elder day care as well as childcare. Employers who provide on-site day care would be encouraged to accept seniors as well.



Chapter IV: **Recommendations for Public Policy Advocacy**

CHAPTER IV: RECOMMENDATIONS FOR PUBLIC POLICY ADVOCACY

“The rapidly graying of America will fundamentally change our culture and present us with some of the most critical policy issues of our times.”

— Paul Hodge, Generations Policy Program, Harvard University

Senior citizens make up an important proportion of the Portland Metropolitan region, and demographic rates show that their numbers will continue to rise over the next few decades. All too often this is viewed as a threat, raising all sorts of social and economic problems, such as the need for suitable housing and flexible health care. Rather, a more positive approach would be to regard the aging of our society as a challenge and opportunity for regional economic growth and for improving our competitive capacity. This next generation of older adults will be the healthiest, most educated, most skilled and most affluent in history.

Seniors can contribute in many ways to a productive and growing society if we view the aging continuum through a different lens. Many European countries refer to this as their “Silver Economy”. Healthy and active seniors contribute to our economy in many ways, including tourism, arts and culture, financial services, and volunteerism/civic engagement.

The overarching goal is to keep seniors active physically and mentally so that this “Silver Economy” remains a community asset, and does not become a community drain. The more actively engaged older adults are, the more likely they will remain independent and enjoy a high quality of life. They may also need less public and private services as they age.

The project team has strongly expressed the opinion that available funds should not be the only driver to determine service options. Level of care must no longer depend on who is setting the rules or controlling the purse strings of public funds.

MAKING THE CASE

Cost savings from independent living:

Cost of monthly care in one’s own home - \$550. Cost in a nursing facility – \$5000 per month. An analysis by the Oregon Association of Area Agencies on Aging and Disabilities finds about half of the people receiving in-home help through OPI probably would transfer to Medicaid if Project Independence went away. Even though Medicaid costs are shared by federal and state governments, the overall cost to Oregon taxpayers would be more because of higher administration costs and because Project Independence relies on volunteers for some of its services.¹¹

Employer and workforce costs:

As stated in Chapter One, the cost of employee care for an elder relative is enormous. To the degree that these caregivers are given respite support, access to adult day care and possibly employer sponsored benefits to assist with daily care, it could translate to a more stable workforce and actually reduce the cost to the employer.

Employer tax credits for hiring seniors:

The American Recovery and Reinvestment Act expands an existing Work Opportunity Tax Credit program to include benefits for business that hire “disconnected youth” and unemployed veterans. Other targeted groups that qualify are food stamp recipients, convicted felons, and veterans on disability. Persons over the age of 60 should be added as a qualified class for employers to qualify for these tax credits.

¹¹ Article in the Oregonian: Independence in Jeopardy by Michelle Cole

Provide tax or college tuition credits to persons who volunteer with social services, schools and non-profits. The Serve America Act recently passed by Congress provides some of these resources.

Investment in family caregivers:

As stated in Chapter Three, resources are critically needed to support family caregivers. The nonprofit and public sectors must recognize the community value gained through these efforts. Not only the significant cost savings, but also the contribution to minimizing a range of senior health issues including depression, abuse, isolation, health/nutrition/personal care, and socialization/physical fitness.

Cost to state for loss of federal Medicare/Medicaid matching funds:

Any reduction in state spending on services to seniors results in a commensurate reduction in federal matching funds to the state. For every \$1 Oregon spends on human services, we get back \$1.66. A recent ECONorthwest economic study on Oregon’s long-term care sector showcases this impact. It found that every \$1 million of forgone federal matching funds creates a tremendous ripple effect leading to significant job losses and local economic activity across the state.

Consequences of cuts in care to seniors:


Any cuts to support services for older adults is likened to **“stepping over a dollar to pick up a dime”** and move Oregon backward, creating unintended consequences. The safety nets paid for with these funds prevent much more expensive care down the road. In-home care through Oregon Project Independence, for example costs less than \$250 per month on average. This pays for home care workers to provide a few hours each week of in-home care to low-income seniors who want to continue living independently. The alternative is a care facility costing around \$5000 per month.

“When it comes to senior care, Oregon is the envy of the nation. Fewer of our residents live in nursing homes than anywhere in the country, thanks to a system that provides cost-efficient in-home care. We can’t afford to lose that.”¹²

Support for Adult Day Care subsidies:

Programs to subsidize the cost of adult day care are an important piece of the continuum of care. Employers can consider adding adult day care to their employee cafeteria benefit plans. Any public program that provides subsidy for child day care should also consider providing subsidy for adult day care.

¹² Children or Seniors? It’s a False Choice: Jerry Cohen and Anita Olsen, oped in the Oregonian.



Chapter V:
**Best Practices —
Local, National,
International**

CHAPTER V: BEST PRACTICES — LOCAL, NATIONAL, INTERNATIONAL

The project team and steering committee conducted extensive research to find examples of **Creative Solutions to Support Seniors and CareGivers**. Their charge was to find the best practices that would impact the most people with the least cost. The practices that meet this criteria and seemed most appropriate for replication or expansion in the Portland metro area include:

Beacon Hill Village – Boston. A revolutionary, all-encompassing concierge service created by residents who want to grow old in the homes they have lived in for years. To preserve their independence, they can turn to the village, as the nonprofit association is known, which helps its 320 members find virtually any service they need – from 24 hour nursing care to help with a wayward cat, often at a discounted fee.

Link to more information: <http://www.beaconhillvillage.org/about.html>

Seattle: Project APEX – Engaging Every Generation for the Public Good. Extensive public research on why and how people volunteer and remain committed volunteers. This is a great research project.

Download a copy here: http://www.seniorservices.org/giving_back/project_apex.aspx

East Multnomah County One Stop, in partnership with Linfield School of Nursing is coordinating a nurse visitation program for homebound seniors hoping to age in place. Nursing students make twice-monthly visits to seniors, check their vitals and medications and do a home safety review. They also have funds to provide emergency supplies for day-to-day needs. Next fall, the program will be expanded to include an “Adopt a Grandparent” program for high school students to fulfill their community volunteer service requirement for graduation. Students will commit to making weekly visits to their new friend, keep a journal, be careful observers of care issues, capture the senior’s life story in an interview process, and present a year-end report on the experience. Students will be able to tap into other student volunteer services for occasional help such as yard and home upkeep.

Intensively trained volunteers from the Mid-Willamette Valley Senior Service Agency in Oregon have become counseling “peers” for distressed older persons in need of mental health support. **The Senior Peer Counseling Program** works with clients, in their own homes, to overcome challenges such as depression, loss, loneliness, substance abuse, and life-change adjustment needs.

The World Health Organization’s Age-Friendly Cities Project in Portland, Oregon: Summary of Findings. The Institute on Aging and the School of Community Health at Portland State University collaborated with the World Health Organization (WHO) on its “Age-Friendly Cities Project.” This unfunded project was designed to identify specific indicators of an age-friendly city, with 33 cities in 22 countries participating from around the world. Portland was the only U.S. city involved in collecting data on the project. The protocol, including research design, focus group scripts, and the analysis plan, was prescribed by the WHO and focused on the following areas: outdoor spaces and buildings, transportation, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, community support and health services.

<http://www.pdx.edu/iaa/>

THE GREEN HOUSE® model creates a small intentional community for a group of elders and staff. It is a place that focuses on life, and its heart is found in the relationships that flourish there. A radical departure from traditional skilled nursing homes and assisted living facilities, The Green House model alters facility size, interior design, staffing patterns, and methods of delivering skilled professional services. Its primary purpose is to serve as a place where elders can receive assistance and support with activities of daily living and clinical care, without the assistance and care becoming the focus of their existence. Developed by Dr. William Thomas and rooted in the tradition of the Eden Alternative, a model for cultural change within nursing facilities, The Green House model is intended to de-institutionalize long-term care by eliminating large nursing facilities and creating habilitative, social settings. Read our mission and vision statements.

<http://www.ncbcapitalimpact.org/default.aspx?id=146>

Health Care Partners: The nonprofit program works like a co-op, in that people pay a membership fee and get cheaper rates from physicians and get an advocate in negotiating medical bills. They also get access to a 24-hour nursing hotline and some specialty services. The pilot program began in Pueblo and is offered in Las Vegas, Colorado Springs and Albuquerque were its next two locations. It has about 300 members.

Health Care Partners charges members \$240 to \$300 a year for an individual and \$600 to \$660 a year for a family. It works with physicians who voluntarily agree to bill members about half the rate of a normal office visit for a private payer. It also acts as a liaison between patients and health care providers on more serious medical issues. There are no income or health qualifications to join. Unlike health insurance, the program tries to help people who pay at the door to do so more affordably. Many uninsured working families, Medina said, don't qualify for government assistance. In some cases, Medina said, small businesses have offered to pay their employees' memberships.

http://findarticles.com/p/articles/mi_qn4191/is_/ai_n24973977
<http://www.ehealthconnection.com/regions/lorain/default1.asp>

The **De Bogen Residential Project** in Harderwijk, Netherlands: This estate, with a range of home types is built around a new multifunctional center. There are subsidized rental accommodations from the housing corporation and houses can be sold or rented. In the multifunctional center, children, people with disabilities, active over 55 year olds, elderly people with additional care requirements and young families come together in the brasserie/bar, the school or the sports hall. The complex in Harderwijk is the first of its kind, bringing together residential functions and care, learning and planning. All around the courtyard garden, bordered by the restaurant terrace, are over 100 homes in different price classes, equipped with the latest electronic gadgetry.

Residents can get assistance and information 24/7 from the "Care Beacon". Medical, dental, physiotherapist specialists are located in the center. Also present on the estate are a child day care center and a community school. The school offers after school care and lets out classrooms to other interested parties. The De Bogen estate was created through a cooperative venture involving over 15 different parties, including the city, housing corporation and care and welfare institutions.

North Rhine/Westphalia: city of Herten: **Vital50Plus project** – exists to develop innovative and need-based solutions for aging residents. The Freie Scholle is a large housing corporation with some 5000 apartments that

specializes in the provision of intergeneration living facilities. The main focus of activity lies in the fields of health and wellbeing, housing, the retail sector and education. To ensure autonomous and independent living for the elderly, the project provides a range of mobile social services, care services, and other support facilities including retailers that offer delivery and mobile shopping. To date, several projects have been successfully implemented including the establishment of an on-line health portal “**vitaport**” containing information for elderly citizens.

Outdoor Fitness Courses for Seniors: Ireland has created several exercise courses located in public parks. The courses have many fitness stops especially designed to keep elderly people more active. Each stop has equipment and directions for use.

National Association of Area Agencies on Aging: 10 “Best Practices” to help communities serve an aging population:

- 1 Preventive health care—including health and “lifestyle” education, immunizations and health screenings—to reduce injuries and the onset of chronic diseases. Include a range of in-home services that will help older adults staying their homes longer.
- 2 Nutrition education to promote healthy eating through a person’s entire lifespan, and community-sponsored nutrition programs like home-delivered meals for older adults who have difficulty preparing their own meals.
- 3 Age-appropriate fitness programs and recreational facilities that offer walking trails, benches, and fitness equipment.
- 4 Safe driving assistance, including larger, easier-to-read road signage, grooved lane dividers, reflective road markings and dedicated left-turn lanes. Include driver assessments and training to promote safe driving for all ages, especially after strokes or other health incidents. Make transportation options available for people who cannot or do not want to drive.
- 5 Special planning and training for public safety personnel and other first responders to help them locate and assist older adults during emergencies and disasters.
- 6 Home modification programs to help people adjust for special needs. Include zoning and subdivision plans that promote a variety of affordable, accessible housing located near medical, commercial and other desired services, as well as shared housing options for older adults and their caregivers.
- 7 Tax assistance and property-tax relief for people in financial need, and programs to protect older adults against scams and elder abuse.
- 8 Job training, re-training and lifelong learning opportunities, plus flexible employment options that will attract and retain older workers.
- 9 Community engagement opportunities, including serving on community boards and commissions, as well as volunteer opportunities in local government and non-profit organizations.
- 10 Single point of access to ALL aging information and services in the community, and the strategic expansion of services that will help older adults age with dignity and independence in their homes and communities.

Texercise is a statewide fitness campaign developed by the Texas State Unit on Aging (TSUA), to educate and involve Texans in physical activity and proper nutrition throughout their lifespans. The Texercise campaign also promotes community events and programs that support fitness in all aspects of life.

<http://www.texercise.com>

Perhaps the most all-encompassing program is the White Crane Wellness Center's Health and Wellness Outreach Initiative based in Chicago. Serving thousands of participants, it offers not only physical activities of choice, but also education and screenings that help older persons become partners in managing their own physical well-being. A White Crane outreach initiative brings services to minority, immigrant, and refugee elderly in a highly diversified service area.

<http://www.whitecranewellness.org/>

Another broad-based program, Take Charge of Your Health, in 14 counties of the Central Savannah River area of Georgia, specializes in hands-on exercise programs, but also puts special emphasis on nutrition. One reason is that, according to state surveys, "A striking 73 percent of men and 66 percent of women aged 55-64 are overweight in Georgia. The problem persists in Georgians 75 years or older."

A private program originating at a Lutheran residence for older persons is also noteworthy for the breadth of its assistance. **The Becoming Center**, in Somerville, NJ, serves older persons in a predominantly middle- and upper-income area. Membership and specialized exercise and training fees help support a wide range of services and opportunities for personalized programs. A Post Rehabilitation program serves persons discharged from medical services and those with chronic conditions or disabilities.

Special-purpose programs are demonstrating the value of close attention to fundamental challenges facing older adults attempting to deal with or guard against certain problems. Portland, Maine, is the headquarters for the "**A Matter of Balance**" program designed to reduce fear of falling and to improve activity levels among older adults who might otherwise be self-limiting because they believe that inactivity protects them against accidents. Research that demonstrates otherwise, and the model for the Maine program, comes from a demonstration project pioneered by the Roybal Center for Enhancement of Late-Life Function at Boston University, Massachusetts.

Use of Technology:

By 2020, 25 percent of the EU's population will be over 65. To respond to this growing demographic challenge, the Council of Ministers approved a Commission plan to make Europe a hub for developing digital technologies designed to help older people continue living independently at home. The proposal will provide some additional €150 million funding to a new European Joint Research Program, resulting in a total investment of over €600 million. Through this new program, companies will be able to develop highly innovative digital products and services to improve the lives of older people at home, in the workplace and in society in general. Smart devices for improving security at home, mobile solutions for vital sign monitoring and user-friendly interfaces for those with impaired vision or hearing -- all of which will improve the quality of life of elderly people, their careers and families. Twenty EU member states, as well as Israel, Norway and Switzerland will participate in this joint research Program.

June 23, 2008, News Report – Aging Well: Europe's Digital Solutions for the Growing Elderly Population

2009 Caregiver Needs Assessment Survey – Significant Findings

You can find the complete survey results online at www.voao.org or www.unitedway-pdx.org

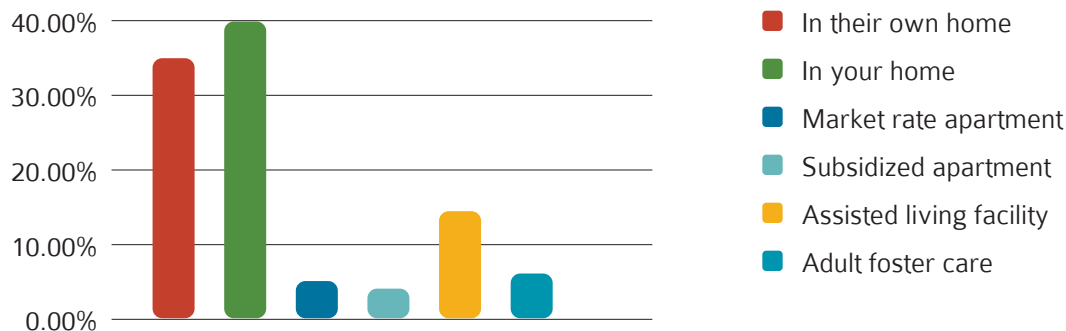
74 Caregivers responded to the survey.

84% of responders are family members who are not paid for providing care. Only 7% of survey responders were non-family, paid caregivers.

81.1% provide care for only one elderly person – the average age of all persons served is 79 years. Of those caring for more than one person, five care for two parents, two a spouse and a parent and three care for a parent and one other relative.

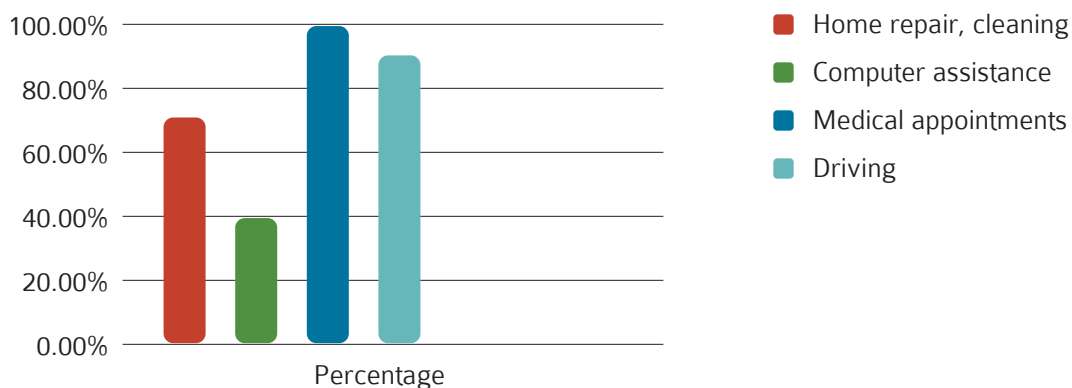
28% provide more than 9 hours of daily care; 30.4% provide 4 to 8 hours of daily care, and 41% provide care for 1 to 3 hours per day. 69% provide care for 4 to 7 days a week. 18% provide care 24/7.

39% of responders provide care in their own homes, while 34% provide care in the home of the person they care for. The remainder live in apartments or care facilities.



Between 50% and 86% of all persons cared for need assistance with Activities of Daily Living, (ADLs). Between 46% and 84% need help with Instrumental activities of daily living (IADLs).

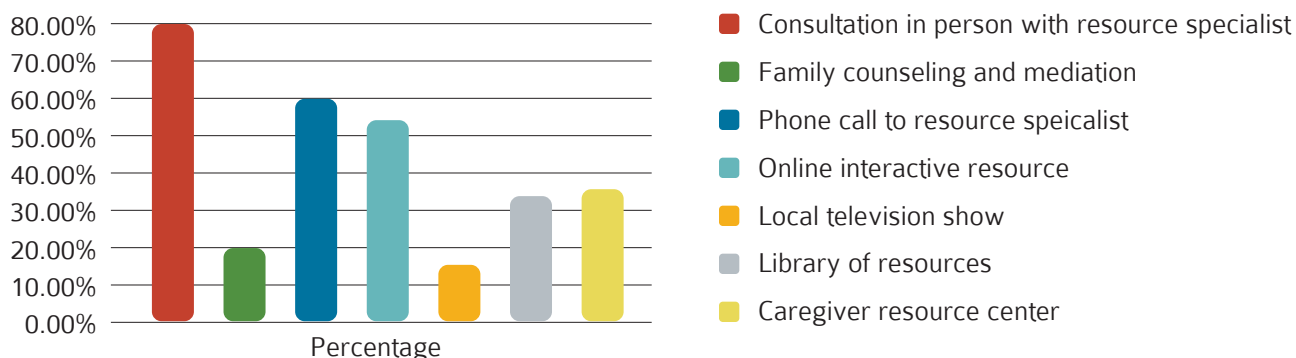
Over 98% provide assistance with Medical Appointments, 87% with driving, 70% for home repair and cleaning and 41% provide computer assistance. Other common support provided included social and entertainment, memory and reminder help, and help with medical care for wounds or medicine management.



The top four places where responders access caregiving information are: 1.) Word of Mouth, 2.) Internet, 3.) Friends and Family, and 4.) Social Service or Public agencies. Other resources listed in comments included AARP, Project Independence, Kaiser Medical, Lambert House, and Lifeworks NW.

Only 22% of responders indicated they tried to access services and were placed on a wait list or told there was no capacity to serve new people. Of these, lack of transportation was mentioned most often.

When asked what resources would be most helpful, as well as what they actually use, most responders indicated either an in-person or phone consultation with a caregiver resource specialist. Online and Internet support was next with over 54% of respondents indicating they use these resources. Other suggestions they offered were: access to drivers at no or low cost; eldercare attorney support; visiting nurses, and hospice resources.



Over 70% indicated they expect to spend more time giving care over the next several months. Most are caring for people with progressive aging conditions that will worsen until end of life.

Over 84% indicated they were very or somewhat prepared to address the needs of the person they care for.

When asked what would make dealing with a sudden change in caregiving needs easier responders suggested the following: (in order of numbers of responses)

- | | |
|--|--|
| Knowing my options – 11 | More time/money – 7 |
| Reliable information that is easily accessible – 9 | Help from others – 6 |
| Respite care – 9 | A counselor or lawyer to work with – 5 |
| Someone to call to discuss issues – 7 | |

People generally are not getting the desired information and don't have the time and/or money to get the resources needed to make value judgments.

Over 77% indicate they have a network of support. Most get support from friends, neighbors and family. Agencies and care facilities provide other support as well as churches; the medical community; co-workers, paid caregivers and respite workers. When asked if their support network offers challenges, over 47% said yes. Most of these challenges are due to family members that do not live near-by, can be unreliable and inconsistent with support, and/or think they can help but don't understand what is really needed but interfere and cause stress.

44% keep a daily journal on the medical condition of the person they care for. This is used primarily to assist with medical visits and to document decline of abilities, etc. Over 76% stated the legal matters for the person they care for are in order. Over 74% have had power of attorney signed; over 76% have prepared advance directives and a will.

When asked if the person they care for has funds to provide for in-home support/respite care/facility placement; 37% responded yes and 37% responded no. Some skipped this question. Over 52% do not have any support benefits to help pay for cost of care.

Over 80% have a team of medical providers assisting with care and support. When asked how this team addresses the needs of the family member, responders indicated frustration at the lack of continuity of care between providers; a sense that the medical team does not understand the needs of the elderly; and that they get minimal support. However, several responders indicated they have very good access and get good information from their medical teams. This was pretty much split 50/50. Those connected to geriatric professionals were very happy. Those going to general practitioners were less so.

One responder stated: **“I find that most of the communication between doctors and facility staff members falls on my shoulders to make happen. There is also a good deal of medical/caregiving jargon that takes some time to get familiar with.”**

Only 50 respondents answered the question about what services would have been helpful to them.

26% — easier access to information (less searching and less trial and error)

24% — more help with services

18% — felt inexperienced and new to care giving and needed the basics

12% — tools to help understand specific progressive illnesses (Alzheimer’s, etc.)

3% — One stop service/resource center

“I knew that this was going to be a difficult experience, but if I had truly realized to what degree this would impact my life, I might have gone a different route. Care giving has its ups & downs, but realize that in our society, it is an unpaid, thankless profession. I feel very sorry for the millions of ordinary Americans like myself, who have yet to experience this situation. I don’t envy them in the least bit. I wouldn’t even wish this on my worst enemy!”

Responders generally gave rave reviews for services they received from the following programs and agencies:

Kaiser Permanente	A Place for Mom	VOAOR Adult Day Care Centers
Legacy Home Health Care	Community Action Program	Cedar Sinai Adult Day Care
Jewish Family & Child Services	Urban League of Portland	Alzheimer’s Association
Aging and Disability Services	NW Pilot Project	Providence Elderplace
OR Project Independence	Project Linkage	Tri-met Lift
Impact NW	(a long time ago)	Meals on Wheels
SSI offices	Visiting Angels	Unlimited Access
AARP	Memory Care	YWCA Sr. Services
Portland Parks and Rec Sr. Services	Veterans Administration	Robison Home
	Elders in Action	LifeWorks NW

Generally, the resources they used fall into these broad categories: support groups, respite care, medical and dental services – especially low income, legal and fiduciary, senior centers for entertainment and socialization, adult day care, transport services, food banks, home nurse visits, church resources, and paid or subsidized in-home care providers.

Over 70% indicated a need for an individual that would come in and give some respite to the primary family caregiver. This was a common theme repeated often in the open-ended responses.

Respondents expressed a lack of information on residential services, respite care and Medicare/Medicaid; followed closely by long term care, recreational and social activities and transportation. Several mentioned the value of a One Stop service/resource center where all information could be accessed.

When asked to detail how services to older adults could be improved they most often mentioned a need for more knowledge-based systems to help find services. This would require a system-wide clearing-house with universal access to information and services. (2-1-1 comes close, but no survey responder mentioned use of this resource.) A One-Stop Center (i.e. Elder Law, Gerontologists, caregiving resources, etc.) would be helpful. People could ask questions and get results at one location, but instead we have people accessing information in many different areas and they often get confusing results on what to do next. The lack of both time and money was also a common response to their ability to access needed services.

“I have said repeatedly throughout this survey how wonderful it would be to have one “one-stop shopping” center I could go to that had all the experts or consultants under one roof, so to speak. They could assess our situation, make recommendations, place a few phone calls, and advocate for her. I would have been willing to pay a fee for this service. These would be people who are experts in their field. You might only deal with one or two front persons or ombudsmen who conferred with other specialists and who were knowledgeable of local, state and federal resources available to meet my mom’s criteria. This could be huge in light of a burgeoning baby boom population lumbering into their old age, and could even go nationwide.”

Responders also indicated a lack of trust in doctors and the medical community to provide adequate care to older individuals. They also expressed frustration with lack of communication between multiple medical and other care providers. A coordinated care approach that involves all persons in the care loop would be a move in the right direction.

This group of responders seem to appreciate the need to take good care of themselves. Over 60% state they exercise regularly. Over 47% carve out time for themselves and over 76% have someone they can call if they need help.

However over 67% have noticed a change in sleep habits. 38% report feeling tired, lethargic and/or uninspired, and a majority report feeling agitated, anxious, frustrated and/or overwhelmed at least some of the time.

The demographics of those responding are included in the attached survey summary appendix. English is the primary language spoken in almost 98% of responders. The others are English and Ebonics, Russian, English and Spanish, and English and Arabic.

Responses to Faith Affiliation: (optional, only 41 chose to respond)

29% — None

25% — Christian – no affiliation listed

9% — Catholic

7% each — Jewish, Protestant, Baptist

Less than 2% — Evangelical Christian, Non-denominational, Presbyterian, Unity Church, United Church of Christ.

Number of people in household:

56% — Two

21% — Three

14% — One

9% — More than three

Spring 2009

It Takes a Village to Live a Life

A Community Assessment on Aging

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