“AMERICA CARES” CHARTBOOK

Prepared by the Altarum Center for Elder Care and Advanced Illness

From data released at November 14, 2016 Forum
Co-Sponsored by Caring Across Generations
“As a nation we really are at a crossroads right now. We can stay with the status quo patchwork system and let the next economic crisis take place in our homes, or we can take advantage of this tremendous opportunity to build the care infrastructure that we need, and support the realities of 21st century families while meeting the country’s soaring future needs for home-based care and more affordable childcare.”

--Sarita Gupta, Caring Across Generations

“There is no doubt that we have it within our power to create momentum for change that is wanted and needed, and to take that forward. Our system is designed to make that possible and we know that money does not produce the best ideas; collective work does.”

--Anne Montgomery, Altarum Institute
The number of older adults over the age of 65 will nearly double by 2050 and the 80+ population is projected to increase 79% from 2010 to 2030 and 44% from between 2030 and 2040.

These changes, coupled with falling birthrates, will create a care gap (see graph). Less than 3 potential caregivers for each older adult in need compared with a 7:1 ratio in 2010.

Meanwhile, labor force participation among women ages 25 to 64, who currently make up 73% of the home care workforce, will increase by only 2 million in the next decade, compared to 6.3 million in the previous decade.

Voter Exit Polling (November 2016): “Which of the following do you think would be MOST helpful for families who are supporting someone who is ill, elderly, or disabled?”

- Financial help for family caregivers: 20
- Easier access to care workers and in-home services: 20
- Making housing suitable for people with disabilities: 11
- All of the above*: 41
- None of the above*: 4
- Don't know/refused: 5

*Volunteered Responses
“When people volunteer “all” that is one indicator that they grasp the depth of the problem and...an indicator that they are not...fully versed in what the most appropriate or easiest bite-sized solution is.”
--Brian Nienaber, The Tarrance Group

“People think this is a huge problem and we are not making very much progress on it.”
--Celinda Lake, Lake Research Partners
“The ‘all of the above’ phenomenon...creates an umbrella for all advocates to be able to say, “we need a system that works for all, and the expertise I am bringing to the table is on workforce, or is on family caregivers, but not in a way where those things are pitted against each other,” [and it is possible], as we have seen in the exit polling information, [that] the solutions people want are the ‘all of the above’ solutions.”

--Josephine Kalipeni, Caring Across Generations
Voter Exit Polling (November 2016): “Which of the following do you think would be MOST helpful for expanding the number of paid care workers who provide quality care for people who are ill, elderly, or disabled?”

<table>
<thead>
<tr>
<th>Opportunity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunities for skills training and career advancement</td>
<td>25</td>
</tr>
<tr>
<td>Benefits including paid time off and retirement savings</td>
<td>16</td>
</tr>
<tr>
<td>Increasing wages to $15 per hour</td>
<td>13</td>
</tr>
<tr>
<td>All of the above*</td>
<td>35</td>
</tr>
<tr>
<td>None of the above*</td>
<td>5</td>
</tr>
<tr>
<td>Don’t know/refused</td>
<td>7</td>
</tr>
</tbody>
</table>

*Volunteered Responses*
“Unless you address wages, benefits, job quality, and also the work environment, and the need for example peer mentorship and day-to-day support with what is really an emotionally taxing job, then simply training more people to do the work does not result in more people staying in the jobs. It actually just results in spending more money on training for people who do not stay in the jobs... Even for those of us in highly rebalanced environments, we still have the next structural challenge in front of us, which is really how to integrate the work that caregivers, paid and unpaid, do with the team that is thinking about the health of the whole person.”

--David Rolf, SEIU 775
National Partnership for Women & Families: Support for Comprehensive 12-Week National Paid Family and Medical Leave Fund

Voter Exit Polling (November 2016): “How concerned are you about being able to afford long-term care for yourself or a family member in the future?”

<table>
<thead>
<tr>
<th>Concern Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not concerned at all</td>
<td>14</td>
</tr>
<tr>
<td>A little concerned</td>
<td>11</td>
</tr>
<tr>
<td>Somewhat concerned</td>
<td>28</td>
</tr>
<tr>
<td>Very Concerned</td>
<td>46</td>
</tr>
</tbody>
</table>

Source: Lake Research Partners for Caring Across Generations. Election Eve/ Night polling
“When we look at family caregiving historically, it has been a bipartisan issue and that sounds great and gives us hope for the future. However, I think that it is often misunderstood because it is viewed very much like volunteerism, it is viewed as something that is free—and it is not free, it comes at a huge cost… We are very committed to the issues of long-term care, long-term supports and services. We have worked in various iterations on long-term care insurance, and home and community-based services is what we are all about… What we need to do is to legitimize the diversity and the people in our direct care workforce, our paid and unpaid workforces in order to get others to see that they are a part of a system.”

--Edwin Walker, Administration for Community Living
“America CARES” Participant Survey (November 2016)

▲ The survey asked respondents to rate their support for 20 policies to aid care-workers in the domains of:
  ▪ Coordination of support
  ▪ Financial challenges
  ▪ Physical, mental, and financial health
  ▪ Balancing work and family responsibilities

▲ Respondents used a 5 point scale, with higher numbers indicating more support (do not support, somewhat support, support, very much support, strongly support).

▲ All policies proposed were well supported; all ratings fell above the mid-point of the scale
“America CARES” Participant Survey: 
Top Five Policies

▲ HOUSING - Ensuring housing is adapted, safe, and suitable for older adults and people with disabilities

▲ RESOURCE REFERRAL - Development of a comprehensive and frequently updated repository of social and supportive services resources available at the local level

▲ IDENTIFY & ASSESS CAREGIVERS - Development and implementation of methods for routinely identifying, assessing and supporting family caregivers within Medicare, Medicaid, and the Department of Veterans Affairs

▲ FLEXIBLE WORKPLACE - Incentives for employers, through tax credits or other means, to routinely offer flexible workplace policies, including flexible start and end times, time-banking, compressed work weeks, and teleworking

▲ EXPAND PACE & OTHER COMMUNITY-BASED PROGRAMS - Piloting of expanded Program of All-Inclusive Care for the Elderly (PACE) programs, or other community-anchored programs for Medicare beneficiaries that expand access to both medical and long-term services and supports (LTSS)

▲ Four of the five speak to coordination of support
“America CARES” Participant Survey: Volunteered Policy Recommendations

- Educate public about long-term care needs and costs
- Enable home remodeling to encourage aging in place – provide a preferred tax
- Develop online training for caregiving – provide competition as incentive
- Develop online matching programs for consumers and paid caregivers
- Eliminate waiting lists for Medicaid home and community-based services waiver programs
- Create metrics to monitor progress in eldercare and caregiver issues
- Consider Medicare expansions: day care, respite, physician time with caregivers, and caregiving back-up
- Allow Medicare Advantage plans to pay for important non-medical services
- Develop monitors to detect in-home abuse (paid or volunteer caregivers)
- Require geriatrics training for physicians and other providers
- Have caregivers involved in “MediCaring Communities” (Altarum Institute)
AARP National Survey (October 2016): Women 50+ anxious about ability to care for themselves as they age, and about retirement security

Please tell me how often you worry about each of the following items – very often, somewhat often, from time to time, or never?

<table>
<thead>
<tr>
<th>Item</th>
<th>Very Often</th>
<th>Very/Somewhat Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>That you will be able to take care of yourself as you age</td>
<td>Under $50K</td>
<td>24%</td>
</tr>
<tr>
<td></td>
<td>Over $50K</td>
<td>15%</td>
</tr>
<tr>
<td>Not having financial security in retirement</td>
<td>Under $50K</td>
<td>26%</td>
</tr>
<tr>
<td></td>
<td>Over $50K</td>
<td>16%</td>
</tr>
<tr>
<td>That Social Security will be there when you retire</td>
<td>Under $50K</td>
<td>20%</td>
</tr>
<tr>
<td></td>
<td>Over $50K</td>
<td>21%</td>
</tr>
</tbody>
</table>

“Women ages 50+ see themselves staying in their home at retirement age... We have seen this consistently over the years... 54% are currently or have been a family caregiver providing unpaid care to an adult loved one... In the new Congress and Administration... bipartisan solutions are needed to support family caregivers. This is not a Democratic or a Republican issue, it is a family issue.”

--Rhonda Richards, AARP

Principles for State-Created Long Term Care Policy Framework:

▲ State long-term care programs would be accessible to all state residents regardless of income;

▲ Guided by a taskforce experts, service providers, consumers, workers, family caregivers, and policymakers, who would take existing disparities of access to care into account;

▲ Benefits of not less than $2,200 per month, with Medicaid or a state program as primary payer, no lifetime caps;
Clinical eligibility tied to one or more limitations in Activities of Daily Living (ADLs), or Instrumental Activities of Daily Living (IADLs), or a demonstrated need for a minimum of two hours of care a day;

Program offers a choice of a flexible cash benefit or paying directly for services;

Consumer protections include matching dollar-for-dollar asset protection for the amount contributed to the program as it relates to Medicaid; and

Workforce development plan must include strategy for recruitment and retention of home care workforce, and overall program costs and benefits must take into account the requirement to pay care workers a living wage.

Available at: http://www.caringacross.org/stories/new-framework-for-state-solutions/
“There are three things you have to do: first you have to define the system well, define the problem well. Second, you have to provide evidence-based solutions, and third, which is probably the hardest part, you have to engage the political will of those in power based on whatever the feeling of the nation or the state is at the time. Gratefully, we have seen some of that happen for three years in a row, and we are hoping for some [more] progress in the next few months.”

--Spencer Blalock, Mississippi Caregiver Task Force/Family Caregiver Platform Project
The Family Caregiver Platform Project developed a volunteer-led, non-partisan, grassroots advocacy movement encouraging policymakers to improve state and federal support for family caregivers of older adults. Along with its national partners, Altarum Institute’s Center for Elder Care and Advanced Illness recruited volunteers to get language on caregiving into the state party platforms in as many states as possible leading up to the national election.
AARP National Survey (August 2016): Women ages 50+ strongly favor giving credit in Social Security benefit calculations to people for the time they take away from work to care for family.
Support is strong for a wide array of policies. When having to make choices, voters and stakeholders most often support:

- **MAKING CAREGIVING MORE POSSIBLE**
  - STREAMLINED RESOURCE REFERRAL
  - MORE POLICY (e.g., in MEDICARE) THAT INCLUDES CAREGIVERS
  - FLEXIBLE WORKPLACE POLICIES FOR EMPLOYED CAREGIVERS
  - FINANCIAL SUPPORTS (e.g., tax credits, credits toward Social Security)
    - PAYING FOR THE WORK
- ADDRESSING CARE WORKER PAY
- STRONGER TRAINING AND CAREER ADVANCEMENT OPPORTUNITIES
  - IMPROVED FINANCING FOR LONG-TERM CARE SERVICES
The Road Ahead for Policymakers, Stakeholders, Researchers, and Advocates...

▲ Remove barriers in existing programs!
▲ Build strong political will for changes that improve choice and the quality of services and coverage options!
▲ Design flexible, community-anchored systems of care and support that can reach all elders and individuals with disabilities in any given community, city, or rural region!
▲ Bring workers, family caregivers, elders, and individuals with disabilities into local planning conversations to help set goals and make tangible progress!