America CARES Online Participant Survey

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Participants in the America CARES Forum were asked to participate in a web-based survey upon registration. 128 individuals responded to the survey.

<table>
<thead>
<tr>
<th>Caregiver Type</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid care-worker</td>
<td>15</td>
<td>12%</td>
</tr>
<tr>
<td>Unpaid care - adult</td>
<td>73</td>
<td>57%</td>
</tr>
<tr>
<td>Unpaid care - child</td>
<td>7</td>
<td>5%</td>
</tr>
<tr>
<td>Unpaid care - both</td>
<td>24</td>
<td>19%</td>
</tr>
<tr>
<td>No care-work</td>
<td>24</td>
<td>19%</td>
</tr>
</tbody>
</table>

62% of respondents indicated they had participated in policy work regarding care workers or family caregivers.
The survey asked respondents to rate their support for 20 policies to aid family caregivers and 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-pt. 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.
Top Five Most Strongly Supported Policies

▲ **HOUSING** - Ensuring housing is adapted, safe, and suitable for older adults and people with disabilities, $M(SD) = 4.37(.90)$

▲ **RESOURCE REFERRAL** - Development of a comprehensive and frequently updated repository of social and supportive services resources available at the local level, $M(SD) = 4.32(.92)$

▲ **ID & ASSESS CAREGIVERS** - Development and implementation of methods for routinely identifying, assessing and supporting family caregivers within Medicare, Medicaid, and the Department of Veterans Affairs, $M(SD) = 4.31(.85)$

▲ **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, $M(SD) = 4.30(.86)$

▲ **EXPAND PACE & OTHER COMMUNITY-BASED** - 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), $M(SD) = 4.28(.88)$

▲ **4 of the 5 are in the category of Coordination of Support**
Participants also asked to *rank* their top three priorities for federal policy.

Each of the 20 policy options was ranked as a top federal priority by at least one respondent.

These two policies were most often ranked number 1:

- **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.

- **CARE WORKER PAY** - Reasonable pay of $15 an hour and benefits for paid care workers.
We asked participants to select and rank three policy priorities. These were the policies that participants selected most frequently.

The most often listed federal policy was:

$ FOR FAMILY CAREGIVERS - Financial support to protect the income and retirement benefits of family caregivers: this could include Social Security credits to offset time spent out of the workforce, or tax credits to defray out-of-pocket costs.

- 29 (40%) respondents ranked this among their top three priorities

The second most prioritized policy was:

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

- 20 (28%) of respondents ranked this in the top three
We asked participants to select and rank three policy priorities for states. These were the policies that participants selected most frequently.

From this perspective the top ranked state policy was:

- **RESOURCE REFERRAL** Development of a comprehensive and frequently updated repository of social and supportive services resources available at the local level
  - 29 (45%) of respondents ranked this among their top three choices

The second most prioritized policy was:

- **CARE WORKER PAY** Reasonable pay of $15 an hour and benefits for paid care workers
  - 21 (33%) of respondents ranked this among their top three choices
Respondents who *worked in policy* most often ranked this as the top federal priority:

- **LONG-TERM CARE PUBLIC FINANCING** - A publicly financed state or federal insurance program to assist older adults, people with disabilities, and their families in paying for long-term care (15%)

Respondents who *did not work in policy* most often ranked this as the top federal priority:

- **MEDICARE SHOULD FOCUS MORE ON CAREGIVERS** - Require CMS to develop and test payment models that incentivize physicians to identify, engage and support family caregivers (16%)
Both respondents who worked in policy and those that didn’t agreed on the top two policy priorities for states:

- **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

- **CARE WORKER PAY** - Reasonable pay of $15 an hour and benefits for paid care workers
Other Policy Options Less Frequently Selected

▲ Coordination of Support
  ▪ Expansion of federal data collection on the experience of family caregivers
  ▪ Ensuring housing is adapted, safe, and suitable for older adults and people with disabilities

▲ Financial Challenges
  ▪ Development of training and certification standards for an Advanced Care Aide category that would expand the scope of practice for direct care workers
  ▪ Provision of support for child care and transportation benefits for full-time care workers

▲ Physical, Mental and Financial Health
  ▪ Create a public-private multi-stakeholder innovation fund for research and innovation to address the needs of caregiving families*
  ▪ Build on the Personal and Home Care Aide State Training (PHCAST) demonstration and other care worker training programs to develop “best practices” training curricula and standards

▲ Balancing Work and Family Responsibilities
  ▪ Creation of locally chartered or national “Caregiver Corps” program allowing trained volunteers to provide practical assistance and companionship to older and disabled adults in the community
Participant Generated Policy Recommendations

- Educate the public about long-term care needs and costs
- Enable home remodeling to encourage aging in place – preferred tax
- Develop on-line training for caregiving – provide competition as incentive
- Develop on-line matching program for consumers and paid caregivers
- Eliminate wait lists for Medicaid waiver programs
- Create measures to monitor progress in eldercare and caregiver issues
- 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
In Summary– An Emerging Consensus?

- We support wide array of policies
- When having to make choices, we tend to support:
  - **MAKING CAREGIVING MORE POSSIBLE**
  - RESOURCE REFERRAL
  - MEDICARE TO PUSH FOCUS ON CAREGIVERS
  - FLEXIBLE WORKPLACE
  - **PAYING FOR THE WORK**
  - CARE WORKER PAY
  - $ FOR FAMILY CAREGIVERS
  - LONG-TERM CARE PUBLIC FINANCING
Caregivers can have the support they want and need

But only if we deliberately build that future!