NEW LENS ON AGING
Changing Attitudes, Expanding Possibilities

GSA 2016 ANNUAL SCIENTIFIC MEETING
NOVEMBER 16-20 | NEW ORLEANS, LA

This Continuing Education activity is jointly provided by The Annenberg Center for Health Sciences at Eisenhower and The Gerontological Society of America.
The National Academies of Sciences, Engineering, and Medicine (NASEM) released a report in September 2016 on family caregiving for older adults.

The report included recommendations for public and private sector policies which would

- support the capacity of family caregivers to perform critical caregiving tasks,
- minimize the barriers that family caregivers encounter in trying to meet the needs of older adults, and
- improve the health care and long term services and supports provided to care recipients.
The Gerontological Society of America was asked by the John A. Hartford Foundation to disseminate the report, amplify its reach, and develop an action plan to move the recommendations to reality.

At its annual scientific meeting in New Orleans, November 16-20, 2016, GSA convened two sessions that focused on the family caregiving report.

The first session provided an overview of the report’s background, findings, and recommendations.
The second session, **Part Two: Digging Deeper**, was an interactive session that connected GSA members with the NASEM study committee members and thought leaders to discuss next steps for the report’s recommendations.

- Five groups, with each group assigned specific recommendations to discuss
- Facilitators were NASEM study committee members and thought leaders with expertise in the field
- Each group reported on its findings
- The “Report Outs” from each group are in the following slides
- Respondent panel offered perspectives
Report Recommendations

1. The Secretary of Health and Human Services, in collaboration with the Secretaries of Labor and Veterans Affairs, other federal agencies, and private-sector organizations with expertise in family caregiving, develop and execute a **National Family Caregiver Strategy** that, administratively or through new federal legislation, explicitly and systematically addresses and supports the essential role of family caregivers to older adults. This strategy should include specific measures to adapt the nation’s health care and long-term services and supports (LTSS) systems and workplaces to effectively and respectfully engage family caregivers and to support their health, values, and social and economic well-being, and to address the needs of our increasingly culturally and ethnically diverse caregiver population.

1a. Develop, test, and implement effective mechanisms within Medicare, Medicaid, and the U.S. Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.

1b. Direct the Centers for Medicare & Medicaid Services to develop, test, & implement provider payment reforms that motivate providers to engage family caregivers in delivery processes, across all modes of payment & models of care.

1c. Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.

1d. Increase funding for programs that provide explicit supportive services for family caregivers such as the National Family Caregiver Support Program and other relevant HHS programs to facilitate the development, dissemination, and implementation of evidenced-based caregiver intervention programs.
Report Recommendations cont’d.

1e. Explore, evaluate, and, as warranted, adopt federal policies that provide economic support for working caregivers.

1f. Expand the data collection infrastructures within the Departments of Health and Human Services, Labor, and Veterans Affairs to facilitate monitoring, tracking, and reporting on the experience of family caregivers.

1g. Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.

2. State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports, and implement similar programs.

3. The Secretaries of Health and Human Services, Labor, and Veterans Affairs should work with leaders in health care and long-term services and supports delivery, technology, and philanthropy to establish a public-private, multi-stakeholder innovation fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families.

4. In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.
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Respondent Panel

**Policy:** Lynn Friss Feinberg, AARP Public Policy Institute, Washington, DC

**Philanthropy:** John Feather, Grantmakers in Aging, Washington, DC

**Government:** Alice Bonner, Dept. of Elder Affairs, Commonwealth of Massachusetts
Healthcare Delivery/LTSS

Facilitators:

Alan Stevens, Ph.D.
Baylor Scott & White Health
Texas A&M University System Health Science Center
Dallas, TX

Jennifer Wolff, Ph.D.
Johns Hopkins University School of Medicine
Johns Hopkins Bloomberg School of Public Health
Baltimore, MD
Healthcare Delivery/LTSS

Recommendations addressed:

1a. Develop, test, and implement effective mechanisms within Medicare, Medicaid, and the U.S. Department of Veterans Affairs to ensure that family caregivers are routinely identified and that their needs are assessed and supported in the delivery of health care and long-term services and supports.

1b. Direct the Centers for Medicare & Medicaid Services to develop, test, & implement provider payment reforms that motivate providers to engage family caregivers in delivery processes, across all modes of payment & models of care.

4. In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.
“Make the case” for including family caregiver information in ongoing health care delivery innovations, ideally based on empirical evidence demonstrating benefit/effect.

- Identify health system “champions” or best practice initiatives.
- Push for new payment models to provide compensation for caregiver assessment activities.
Practice settings that have adopted a team-based care approach will be more prepared to be inclusive of family caregiver and may serve as the “early adopters”

- Even team-based models of care may be limited by the lack of available workforce.

Practice settings across the continuum, as well as diverse healthcare professionals (e.g., nurses, social workers, physicians) will need tools to achieve the goal of caregiver identification and assessment.

- As an example: APA has a [toolkit](#).
Economic Support

Facilitators:

Donna Wagner, Ph.D.
New Mexico State University
Las Cruces, NM

Josh Wiener, Ph.D.
RTI International
Washington, DC
Economic Support

Recommendations Addressed:

1e. Explore, evaluate, and, as warranted, adopt federal policies that provide economic support for working caregivers.

4. In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.
Economic Support – Report Out

- Tax credits or deductions for caregiving
- Social Security credits for caregiving
- Support expansion of participant-directed care under Medicaid which allows hiring relatives and provide training.
- More help through Employee Assistance Plans (EAP), including financial advisors and Flexible Spending Account
- Expand Family and Medical Leave Act – take advantage of state action
Research

Facilitators:

Sara Czaja, Ph.D.
University of Miami
Miami, FL

Laura Gitlin, Ph.D.
Johns Hopkins School of Nursing
Johns Hopkins School of Medicine
Baltimore, MD

Katie Maslow, MSW
The Gerontological Society of America
Washington, DC
Recommendations Addressed:

1g. Launch a multi-agency research program sufficiently robust to evaluate caregiver interventions in real world health care and community settings, across diverse conditions and populations, and with respect to a broad array of outcomes.

3. The Secretaries of Health and Human Services, Labor, and Veterans Affairs should work with leaders in health care and long-term services and supports delivery, technology, and philanthropy to establish a public-private, multi-stakeholder innovation fund for research and innovation to accelerate the pace of change in addressing the needs of caregiving families.

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Research – Report Out

- Ensure current interventions are addressing the changing needs of caregivers for diverse caregivers and diverse caregiving situations

- Implementation practices – identify strategies on how to adapt and integrate evidenced-based interventions in actual practice settings at multiple points of entry

- Redirect funds to translations projects such as the ADSSP program

- Funds to go beyond Alzheimer’s Disease
Research (cont’d)

- New areas for intervention development:
  - Families caring for multiple people and multiple family members involved in care; how best to identify caregivers; caregiving across the lifespan; broaden our outcomes – other stakeholders – e.g., hospital systems, employers
  - Preparing people for end-of-life and advanced directives discussions
  - Evaluate in real world contexts

- Data on how many practices are using EHR systems to identify family caregivers

- Collect more robust data on how many caregivers are using current programs and services; which ones; barriers to access
Community Based Services

Facilitators:

Debra Cherry, Ph.D.
Alzheimer’s Greater Los Angeles
Los Angeles, CA

Lisa Gwyther, M.S.W.
Duke University Family Support Program
Durham, NC
**Community Based Services**

**Recommendations Addressed:**

1c. Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.

1d. Increase funding for programs that provide explicit supportive services for family caregivers such as the National Family Caregiver Support Program and other relevant HHS programs to facilitate the development, dissemination, and implementation of evidenced-based caregiver intervention programs.

2. State governments that have yet to address the health, economic, and social challenges of caregiving for older adults should learn from the experience of states with caregiver supports, and implement similar programs.

4. In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.
Community Based Services – Report Out

- Encourage more inter-organizational partnerships and collaboration within communities.
- Identify local cancer/heart associations and others who are responsive to caregivers (e.g., Alzheimer’s Association).
- Encourage community to better link CBOs with major healthcare organizations (e.g., senior centers, AAAs to coordinate with health orgs).
- Fund CBOs so that they can respond to the demand for referrals from managed long-term care organizations.
- Identify, fund, and publicize a central spot where caregivers can find local community support.
- Develop training programs to teach CBOs about health care services, such as Linkage Lab and ACL business acumen program.
- Have a community caregiver consortium at the local level, e.g., California has statewide and local caregiver coalitions.
- Sustain demonstration programs through state policies (such as the work in Connecticut).
Community Based Services (cont’d)

- Train health and social service providers on how to work with family caregivers. Develop simple, short staff trainings.
- Insert caregiver focus within other innovation programs, for example, Care Transitions program.
- Provide health care workforce with a simple informational handout to give to family members about their role as caregiver.
- Need rapport and education within the community; information alone is not sufficient.
- Work with discharge planners and care transition coaches.
- Visit physician offices for educational detailing (like drug rep visits) to train physicians on needs of caregivers.
- Raise awareness about the CMS code for caregiver assessment.
- Better coordination of care and coordination of referrals among care recipient’s various doctors.
- Develop proactive system where providers place a call to caregiver rather than passive referral.
- Programs are available to teach healthcare orgs. about CBOs.
Community Based Services (cont’d)

- Need to consider the socio-economic status at the individual, family, and neighborhood levels since this impacts how people access resources.
- Be aware of different norms around privacy and autonomy between disabilities community and caregivers of older adults in need.
- Cite the NASEM report in our papers, publications, newsletters, etc.
- Use report to bolster need for research on caregiving.
- Encourage private philanthropy to use recommendations from the report to guide local grant making around family caregiving.

Role of GSA moving forward:
- GSA should compile and report on what other states are doing. Here’s what we did, and here are the benefits we’re seeing. Help people starting on the ground level to jump the learning curve.
- Connect GSA members to go to professional conferences and meetings to talk about the report and caregivers.
Workforce

Facilitators:

Karen Schumacher, Ph.D., R.N.
University of Nebraska Medical Center
Omaha, NB

Amy York
Eldercare Workforce Alliance
Washington, DC
Recommendations Addressed:

1c. Strengthen the training and capacity of health care and social service providers to recognize and to engage family caregivers and to provide them evidence-based supports and referrals to services in the community.

4. In all the above actions, explicitly and consistently address families’ diversity in assessing caregiver needs and in developing, testing, and implementing caregiver supports.
Workforce – Report Out

- Strategies for education and training of workforce
  - Workforce learning needs are inseparable from what caregivers need to know
  - Use resources available – GWEP (free, online continuing education credits), ELNEC, FCA, Alzheimer’s Association
  - Expand and disseminate existing toolkits like the Life Course modules
  - Use telehealth
Strategies for System Change

- Embed workforce training within ongoing system changes
- Focus on manageable pieces
- Focus education on caregiver role in preventing 30-day readmissions; Get hospital by-in as important to bottom line
- Use available billing codes
- Be aware of ongoing pressures within health systems, including time constraints in primary care
- Link workforce preparation for engaging caregivers to JCO evaluations
Workforce (cont’d)

- **Use of Outcome Data**
  - Not only do we need data on who is trained, but also data on the impact of training on older adults and caregivers
  - Show near-term and long-term outcomes
  - Analyze outcome data in terms of subpopulations – not generic “caregivers”
  - Link outcomes to JCO reviews

- **Advocacy with state and federal governments**
  - Broaden CARE Act
  - Remember: Change involves politics, media, and public support
Thank you to our session attendees, table facilitators, respondent panel, and especially to the NASEM study committee chair, Dr. Richard Schulz.

Thank you also to The John A. Hartford Foundation for funding this dissemination project.
For more information on family caregiving, please visit the GSA website at [www.geron.org - family caregiving](http://www.geron.org - family caregiving).

Follow us on twitter: @geronsociety

We would like to hear your ideas for dissemination and next steps for the NASEM family caregiving report, *Families Caring for an Aging America*.

Please contact Patricia D’Antonio, GSA Senior Director for Professional Affairs, at [pdantonio@geron.org](mailto:pdantonio@geron.org).
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