

CAREGIVING

— 2031 —

SCENARIO TOOLKIT

Exploring caregiving futures to improve decision-making today



About this Project

With support from the Robert Wood Johnson Foundation, the Institute for the Future (ITF) has created a set of three scenarios that explore the future of caregiving in the year 2031 and are intended to provoke a wider discussion about current alternatives to improve support for caregivers. The project, which focused primarily on caregiving for older friends or relatives, began with a literature review, along with a dozen structured interviews with experts representing a diverse set of experiences and perspectives on caregiving. The literature review and interviews were combined with ITF's existing research to develop a set of forecasts that describe how the key drivers of change over the next 10-15 years are likely to impact the caregiving experience. The forecasts informed the three video scenarios, each focused on a different strategy for improving the future of caregiving. In June 2016, the project culminated with a workshop using the scenarios to provoke conversations and a draft of this toolkit to drive actions to improve future experiences for caregivers and care recipients.

About Institute For The Future

The Institute for the Future (ITF) is an independent, nonprofit strategic research group with more than 47 years of forecasting experience. The core of our work is identifying emerging discontinuities that will transform global society and the global marketplace. We provide organizations with insights into business strategy, design process, innovation, and social dilemmas. Our research spans a broad territory of deeply transformative trends, from health and health care to technology, education, the workplace, and human identity. ITF is based in Palo Alto, California.

Acknowledgements

Authors: Richard Adler, Miriam Lueck Avery, Ben Hamamoto, Rachel Maguire

Contributing Researchers: Mary Cain, Rod Falcon, Marina Gorbis, Katherine Haynes-Sanstad, Bob Johansen, Bradley Kreit

Executive Producer: Jean Hagan

Project Manager: Cindy Baskin

Creative Direction: Dylan Hendricks, Robin Bogott

Design and Illustration: Karin Lubeck, Trent Kühn, Sheena McNeal, Robin Weiss

RWJF Program Officers: David Adler, Tara Oakman

Cover images: ITF, Family Caregiving Alliance, Liftware (Liftware.com)

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TAKE ACTION NOW TO AVERT A CAREGIVING CRISIS

In recent years, the issue of caregiving has received far more attention than it ever had before. A steady stream of studies and newspaper articles have described the scale of caregiving and the challenges faced by caregivers; a number of states and local communities have passed laws to support caregivers; and politicians have begun to talk about caregiving as a crisis needing action. **But what kind of action is needed?**

To explore this question, the Institute for the Future (ITF) developed a set of three scenarios for caregiving in the year 2031 that portray different paths away from crisis: the first explores new social and financial arrangements for caregiving; the second examines the role of technology in supporting caregivers; and the third looks at the implications of integrating informal caregiving with the formal health care system. The scenarios focus primarily on care provided by family members for older adults, who represent the majority of care recipients.

No single intervention will “solve” the problem of caregiving—in fact, it’s not a single problem, but many complex needs. But some combination of the strategies described in our scenarios may help alleviate the burden on caregivers and improve the quality of caregiving.

These three scenarios are intended to provoke serious consideration of strategies—including those portrayed in the scenarios and others—that will guide actions that can be taken now to avert this crisis.

CAREGIVING: TODAY TO 2031

A 2015 survey found that 43.5 million adults in the U.S. (18.2% of all Americans over age 18) provided unpaid care to a friend or family member in the past year.

We also know that caregiving can be a difficult, stressful job, and that most caregivers get little help, recognition, or compensation. In fact, much caregiving is invisible, disconnected from the professional health care system and provided in isolation. It may even involve providing complex medical care with little training or support. Working caregivers often face conflicts with their jobs, and many of those providing care must cope with their own physical and psychological health needs exacerbated by the demands of caregiving.

A growing number of experts have pointed to a coming “caregiving crisis.” Demographic trends clearly indicate that the need for caregiving will grow even larger between now and 2031. As the population continues to age, and as medical advances continue to prolong life, the need for caregiving is certain to grow substantially. Some have forecast a looming “caregiving cliff”



when the number of older Americans needing care greatly exceeds the supply of traditional caregivers (i.e., younger family members).

See Appendix 1, page 13, for more data about caregiving.

HOW TO USE THESE SCENARIOS

This toolkit is your guide to exploring the complex issues of caregiving and to identifying promising options to address these challenges using the three future scenarios as a starting point. These scenarios/videos can be viewed at www.iff.org/caregiving2031

WHY FUTURE SCENARIOS?

These scenarios are not predictions or best or worst case scenarios, but rather they examine plausible futures for the caregiving experience. They are intended to help policy makers, advocates, and other interested parties expand their thinking about the current and future challenges of caregiving and to make better decisions in uncertainty by considering a broader range of possibilities.

The scenarios are set in the future, 2031, which is far enough out to go beyond the constraints of the present, but not so far out that the issues are unrecognizable. 2031 also is close enough that actions taken today can make a difference in moving us closer to a preferred future. These scenarios help us imagine how a crisis in caregiving could plausibly be averted.

Each scenario is presented by a video and summarized by a brief text description. Discussion questions help you explore the scenarios through reflection and group conversation. We also include signals of change today—concrete examples that may be small today but have the potential to inspire, be replicated, and scale. The future is always in motion, so we offer search terms for you to find your own signals. Each scenario has a companion insight exercise to help you move from foresight to insight to action.

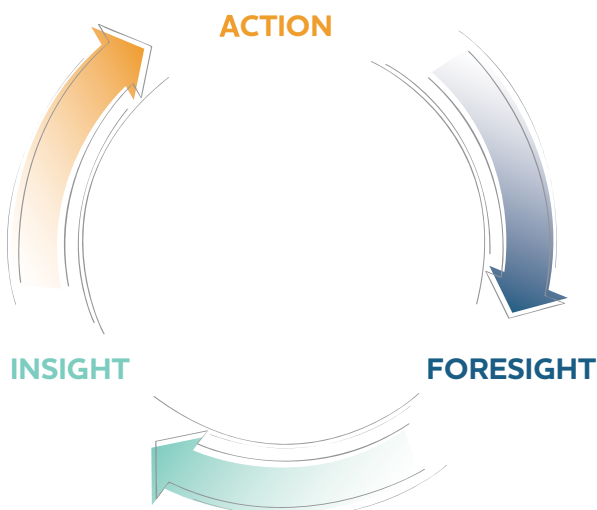
NEIGHBORS CARE



ANGELS IN THE FLOORBOARDS



CARER ACT



◀ **Much of IFTF's work is based on the concept of "Foresight to Insight to Action."** By portraying possible futures, these scenarios are intended to provide foresight. By working with the scenarios to explore their implications in the context of an individual's or group's particular interests, it is possible to generate the insights which can then lead to constructive action.

IF YOU HAVE ...

1-2 HOURS

- Expose your board of directors
- Run a community meeting
- Frame a conference panel

1-2 DAYS

- Integrate **FORESIGHT** into strategic plans
- Set a new direction
- Start a new initiative

WATCH THE SCENARIOS



www.iff.org/caregiving2031

Discuss questions & signals
on pages 4, 6, 8

Explore each scenario and
develop **INSIGHT** using the
exercises on pages 5, 7, 9

Identify 3 simple actions
you can take to follow up
on your discussion

Complete **ACTION** exercises that
challenge you to think across
scenarios to address complex
cases on pages 10–11

**LEARN
MORE**

Appendix I: Caregiving Facts
Appendix II: Resources for Further Reading & Exploration

SCENARIO 1: NEIGHBORS CARE

In a world where social innovators, policy makers, and the financial industry have acted to develop new markets and models of caregiving, a generation in which childlessness is normal is redefining what “family” caregiving means.

Joe has led a good life, but now at age 78, he is facing a serious illness with no children or immediate family to care for him. He reviews the resources that he hopes to call on to provide the care he expects to need, including credits for his contributions of time to a “carebank” in his community,

a life insurance policy with an accelerated care benefit, and the recently passed federal Catastrophic Long Term Care program. He seems to have his future figured out, but he worries about his friends who don't have as many resources to call on.

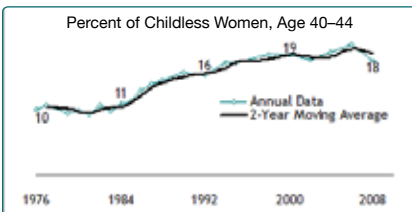


Watch the video: www.iff.org/caregiving2031

DISCUSSION QUESTIONS

- When Joe's circumstances are more representative, what happens to “family caregiving”? What has changed? What has not?
- A networked care model works best for those with limited needs for care. However, as needs become more intense, this solution starts to strain and break. Are there parts of a networked care model that might be adapted to support sustained, intense care?

SIGNALS OF CHANGE TODAY



Nearly one-in-five American women ends her childbearing years without having borne a child, compared with one-in-ten in the 1970s.

www.pewsocialtrends.org/2010/06/25/childlessness-up-among-all-women-down-among-women-with-advanced-degrees



Members of the linkAges TimeBank in Palo Alto, CA, including seniors and family caregivers, can get support for personal needs through exchanges of services with other members that focus on their interests and skills.

www.patch.com/california/mountainview/join-the-linkages-timebank_e66823d5



In February 2016, the multi-stakeholder Long-Term Care Financing Collaborative released its final recommendations for providing effective and efficient long-term care delivery and financing, which included a universal catastrophic insurance program.

Image: kahuku.hhsc.org
www.convergencepolicy.org/ltcfc-final-report/



The future is always in motion! Search online for “long term care financing,” “gig economy,” “care grid,” and “time banking” to find recent news and stories in your location.

INSIGHT ACTIVITY: RESOURCE MAPPING

This model of caregiving works best for those with strong social ties or good financial sense. How might this scenario work for those without much social or monetary capital? If this exercise has you challenging your assumptions, it's working.

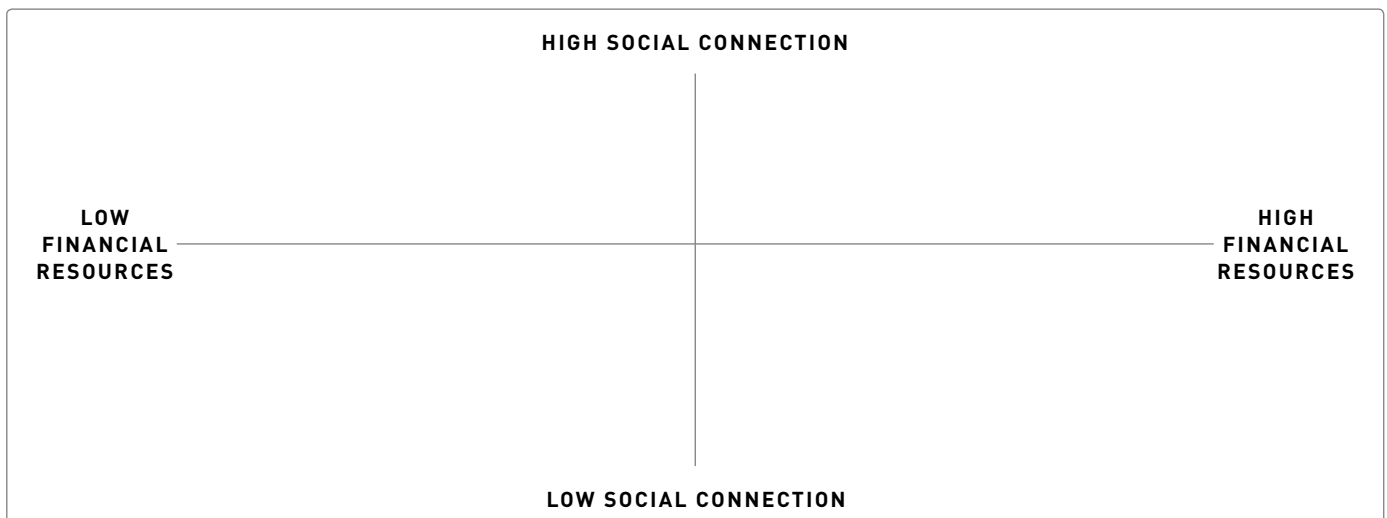
1 | MAP where Joe falls on the field of social and financial resources in 2031. Mark that with a (J). Consider how the events depicted in this 2031 scenario might impact Joe's social and financial resources. As his disease progresses, does he move from one quadrant to another?

2 | IMAGINE another care recipient—this could be you, a client, or a representative of some target population. Map where they fall in 2016 on the field of social and financial resources and mark that above with their initial. Describe them to the right.

3 | CONSIDER how the events depicted in this scenario might affect the care recipients you know—and how they might call on a network of resources to care for them. Do they move from one quadrant to another between now and 2031? What does that mean in their lives?

4 | DESCRIBE the different motivations for the network of caregivers who might help the care recipient you know between now and 2031. What might move them from one quadrant to another?

5 | WHAT ACTIONS can be taken to move (or keep) the care recipient to the top half of the field? Jot them down to the right and circle the top 3 that generate the most urgency and possibility for your group.



SCENARIO 2: ANGELS IN THE FLOORBOARDS

Technology has a role to play in alleviating the burden of caregivers and improving the quality of caregiving. Caregivers, care recipients, policy makers, and technologists need to work together to navigate how big a role technologies play and anticipate the tradeoffs that may come with it.

Lauren has a demanding, full-time job, two active kids, and a mother with Parkinson's disease who lives alone and is increasingly dependent on her daughter for care. Since her mother Carolyn lives alone over an hour away, Lauren relies on several technologies to help her help her mom, most of which were not specifically developed to support caregiving. OSCAR, an intelligent digital assistant, coordinates and schedules multiple family activities including Lauren's caregiving responsibilities; a "smart home" system includes the ability to monitor Carolyn's activities and health status; and CLEO,

a mobile "telepresence robot", lets Lauren (and others) visit virtually and will soon be equipped to provide some physical assistance.

Lauren knows that these technologies are not a perfect substitute for being there in person, but they can help her fill in the gaps and make it easier for her to juggle her multiple roles. And Lauren is aware that that new technologies almost always bring challenges of their own even while they solve other problems.



Watch the video: www.iff.org/caregiving2031

DISCUSSION QUESTIONS

- If robots and other advanced technologies begin to play an important role in caregiving, what lessons can we learn from the digital divide of past decades about ensuring equity of access to these new tools, especially for those who lack resources or skills to use technology fully?
- As the ability to monitor the activities of frail elders becomes more powerful, are safeguards needed to protect their privacy and dignity?

SIGNALS OF CHANGE TODAY



GiraffPlus is a robot developed in Sweden that serves as a vacuum cleaner, standing mirror, a video-chat platform for family and doctor visits, and a health monitor that can measure and record vital signs such as blood pressure and temperature.

www.outerplaces.com/images/user_upload/sweedencare.png



Harvard researchers have developed "soft" powered exoskeletons in the form of pants to assist people walk or climb stairs.

www.ryortho.com/wp-content/uploads/2014/09/OneHip_LEAD_Exosuit_WEB.jpg



Amazon's Echo/Alexa has been used to help blind people access information—and next-generation virtual assistants from Google and the makers of Siri promise to handle complex tasks without human intervention.

www.life-after-60.com/wp-content/uploads/2015/05/Amazon-Echo.jpg



The future is always in motion! Search online for "cognitive assistants," "eldercare robotics," "ambient assisted living," "self-driving cars," and "affordable exoskeletons" to find recent inventions and developments.

SCENARIO 3: CARER ACT

In 2016, 46% of family caregivers perform complex medical and nursing tasks for care recipients—with little recognition, training, or support. In a future where caregiving is integrated into the formal health care system through a national Caregiver Advise, Record, Enable, and Reimburse (CARER) Act, respect and opportunities for caregivers come with increased demands for documentation and interaction.

When Jorge's grandfather suffered a debilitating stroke, Jorge, a 20-year old college student, became his grandfather's primary caregiver—even though he knew little about how to provide the complex care that his grandfather needed when he returned from the hospital. But his grandfather's medical group offered to train Jorge to be a "certified caregiver," and even provided him with a stipend to support his training and caregiving and continued education.

As he gained skills, Jorge became a real member of his grandfather's care team. He was happy to learn that the integration of caregivers like him with the medical system had begun to have a positive impact on things like hospital admission rates for frail elderly patients, but the formalization of family caregiving has had its own drawbacks.

DISCUSSION QUESTIONS

- If health care spending goes up to pay for caregivers of patients who are very frail, how likely is it that overall healthcare costs will go down?
- Jorge and his grandfather benefit in many ways from the recognition of Jorge's role by the formal health care system. How might those who don't receive as much medical attention fare in this scenario? What are the options for integrating family members who care for those who are not frail or not suffering from serious illnesses that need continuous medical care?



Watch the video: www.iff.org/caregiving2031

SIGNALS OF CHANGE TODAY



The Caregiver Advise, Record, Enable (CARE) Act, passed in over 30 states, requires hospitals to identify the family caregiver on their loved one's medical record, inform caregivers of an upcoming discharge, and provide instruction for any medical tasks the caregiver will perform.

<http://blog.aarp.org/2016/06/07/stepping-up-to-support-family-caregivers/>



New models for health care delivery systems from current health reform, such as the Patient-Centered Medical Home and Accountable Care Organizations, put more emphasis on the patient's environment beyond the clinic and the hospital, including the role of caregivers.

www.carolinapedswim.com/image/image_gallery?uid=35ff74f2-7791-4087-9218-3a7ee1ae1042&groupId=10406&t=1406813975712



Virtual reality technologies are being used to teach mastery and empathy, which are difficult to achieve through conventional training methods. The Advanced Dementia Experience (ADVDE), uses VR to engender an empathic understanding of the experience of dementia.

www.mcall.com/health/mc-virtual-dementia-tour-sacred-heart-20141117-story.html
Source on ADVDE www.opaque.media/cover-vde



The future is always in motion! Search online for terms such as "CARE Act," "virtual reality training," and "local policy caregiving support" to find recent policies and innovations in your area.

INSIGHT ACTIVITY: WHEEL OF CONSEQUENCES

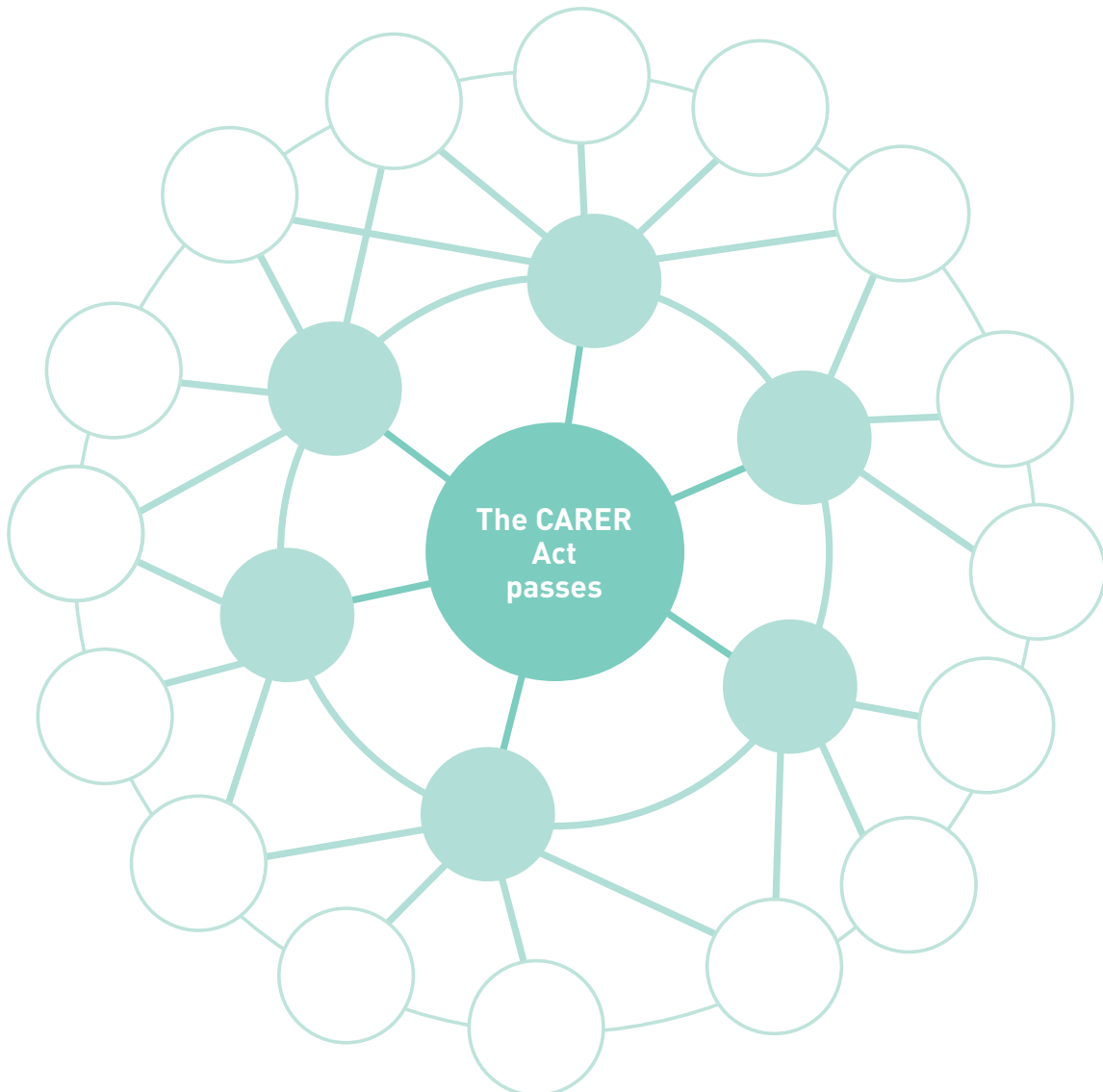
Efforts to formalize informal care can unlock many benefits, but can also lead to unintended consequences. Use this Wheel of Consequences to think through how a national CARER Act could affect caregivers and care recipients—directly and indirectly.

1 | In the light green circles around “The CARER Act Passes” in the diagram below jot down 6 things you would want from such a piece of legislation—think of things like “respite care” or “compensation.” What are the biggest issues that the formal integration of caregiving into the health care system might address? These are first order consequences: direct outcomes.

2 | For each of these 6 things, what might happen next? These are the second order consequences—like stakeholders reacting, new tasks that might emerge, or other unintended consequences. Jot these down in the next ring of circles.

3 | What might be the most surprising outcome of all those possible developments? Note these surprising outcomes around the margins.

4 | When advocating for policy change, are there strategies you might reconsider or reinforce after this exercise? Take a moment to capture 3 ACTIONS you might want to take today to guard against unintended consequences.



ACTION: MAKE THE FUTURE TODAY

We imagine alternative scenarios to push ourselves: the future may include all of these approaches not only to avert a crisis but to support caregivers in amazing ways. There are also complex, challenging cases of caregiving where none of these scenarios offer true solutions. This section is designed to help you synthesize insights and actions across the three scenarios and plan actions to address these most challenging cases.

1 | HARVEST ACTIONS FROM SCENARIOS

Return to your notes on pages 5, 7, and 9. Write your ACTION highlights on stickies or directly into the space below.

2 | CHOOSE A CASE

Challenging and complex cases will require strategies gleaned from all three scenarios—and more. Chose one of these complex cases, or work on another complex challenge you face in your own work:

- » **Providing dementia care**
- » **Remote caregiving for a recipient 1000+ miles away**
- » **Caring for an individual with multiple complex medical conditions**
- » **A single caregiver responsible for caring for 2 or more recipients**
- » **A frail caregiver**

3 | DESCRIBE

Describe the characteristics and circumstances of the caregiver(s) and care recipient(s). What are their most critical challenges?

4 | RECRUIT RESOURCES

What resources (e.g., social, financial, technological) are currently available to support these caregiving challenges? What new resources could be brought to bear between now and 2031?

CURRENTLY AVAILABLE	NEW RESOURCES BY 2031

5 | STEPS

What steps could be taken NOW to accelerate the creation and deployment of these new resources to address the challenges identified above?

CAREGIVING FACTS

Definition of caregiving:

Caregiving is care for a relative or friend to help them take care of themselves. This may include helping with personal needs or household chores, managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This report focuses on caregiving for older adults and especially on care that is currently unpaid.

Prevalence:

43.5 million adults in the US—about 18.2% of Americans over age 18—reported providing unpaid care in the previous 12 months. Approximately 34.2 million Americans provided care to an adult age 50 or older.

Who receives care today?

Nearly half of care recipients (47%) are over the age of 75, while 86% are age 50 or older. The oldest recipients require more caregiving time on average.

- Three-fifths (59%) of care recipients have a long-term physical condition and a quarter (26%) have a “memory problem.”
- A large majority of caregivers provide care for a relative (85%), with 49% caring for a parent or parent-in-law. About 10% are caring for a spouse.

Who provides care today?

About 80% of care at home is provided by unpaid (informal) caregivers, while paid caregivers provide 20%.

- The majority of caregivers are female (60%); but 40% are male. More than half of caregivers (53%) are age 50 or older. Nearly one in ten caregivers (7%) are over age 75.
- Working caregivers: Six in ten caregivers were employed at some point during the previous year and almost all of them reported having to make “workplace adjustments” (such as cutting back on working hours or taking a leave of absence) as a result of caregiving.

- Remote caregivers: While three-quarters of family caregivers live with or within 20 minutes of their care recipients, approximately 11% live an hour or more away.
- Complex caregiving: At least half of all caregivers have been called on to perform “medical/nursing tasks for care recipients with multiple chronic conditions,” which involved such tasks as managing multiple medications, wound care, giving injections or intravenous therapy, incontinence support, and serving as care coordinators. Caregivers often found themselves doing these complex tasks with little training or support from medical professionals.

Future projections:

Individuals 85 years and older—the oldest old—are one of the fastest growing segments of the population. In 2015, there are an estimated 5.9 million people 85+ in the United States. This figure is expected to increase to 19.4 million by 2050. This means that there could be an increase from 1.6 million to 6.2 million people age 85 or over with severe or moderate memory impairment in 2050.

- The Caregiver Support Ratio—the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 or older—is projected to drop from approximately 7:1 in 2010 to 4:1 in 2030.
- Six factors expected to drive demand for caregiving are: growth in the older population; extended years of disability; increased ethnic diversity; reduced economic status; health reform; and a decline in number of available caregivers.

The Family Caregiving Alliance maintains and regularly updates collections of caregiving statistics:
www.caregiver.org/caregiver-statistics

APPENDIX II

RESOURCES FOR FURTHER READING & EXPLORATION

Online Resources

This project keeps a Pinterest board of recent stories and studies that can be accessed here:

www.pinterest.com/adler0500/future-of-caregiving

CAREGIVING RESEARCH

Caregiving in the U.S. 2015, AARP & National Alliance for Caregiving, June 2015,

www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

Susannah Fox, Maeve Duggan and Kristen Purcel, Family Caregivers are Wired for Health, Pew Research Center, June 20, 2013,

www.pewinternet.org/files/old-media//Files/Reports/2013/PewResearch_FamilyCaregivers.pdf

Rajiv Mehta and Dawn Nafus, Pilot Study Report, Atlas of Caregiving, April 2016

http://atlasofcaregiving.com/wp-content/uploads/2016/03/Study_Report.pdf

Donald Redfoot, Lynn Feinberg, and Ari Houser, The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers, AARP Public Policy Institute, August 2013,

www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html

Susan C. Reinhard, Carol Levine and Sarah Samis, Home Alone: Family Caregivers Providing Complex Chronic Care, AARP Public Policy Institute/UHF, October 2012,

www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

Double Duty: The Caregiving Crisis in the Workplace, Ceridian Lifeworks, 2015,

www.ceridian.com/resources/white-papers/caregiving-in-the-workplace.html

PUBLIC POLICY

Lynn Feinberg, Policies and Family Caregiving, Institute of Medicine, Committee on Transforming End-of-Life Care, May 29, 2013,

www.iom.nationalacademies.org/~media/223BEFC1E12545FFA3EB621582E314E6.ashx

Karen Davis, Amber Willink, and Cathy Schoen, Medicare Help At Home, Health Affairs, April 13, 2016, www.healthaffairs.org/blog/2016/04/13/medicare-help-at-home

Anna Gorman, Hospitals Required To Keep Caregivers In The Loop, Kaiser Health News, January 6, 2016, www.khn.org/news/hospitals-required-to-keep-caregivers-in-the-loop

The Key to Economic Growth is Building a Care Grid, New America Weekly, May 1, 2015 www.newamerica.org/new-america/the-key-to-economic-growth-is-building-a-care-grid

TECHNOLOGY & CAREGIVING

Richard Adler and Rajiv Mehta, Catalyzing Technology to Support Family Caregivers, National Alliance for Caregiving, 2014,

www.caregiving.org/wp-content/uploads/2010/01/Catalyzing-Technology-to-Support-Family-Caregiving_FINAL.pdf

Louise Aronson, "The Future of Robot Caregivers," The New York Times, July 24, 2014,

www.nytimes.com/2014/07/20/opinion/sunday/the-future-of-robot-caregivers.html

Is the Future of Robotics in Caring For the Elderly? Outer Places, July 21, 2014,

www.outerplaces.com/science/item/4966-the-future-of-robotic-caregivers

Books

CAREGIVING ISSUES

Joseph Gaugler and Robert Kane (eds), *Family Caregiving in the New Normal*, Academic Press, 2015.

Henry Moss, *The 2030 Caregiving Crisis: A Heavy Burden for Boomer Children*, BookBaby, 2015.

Ai-Jen Poo, *The Age of Dignity: Preparing for the Elder Boom in a Changing America*, The New Press, 2015.

TECHNOLOGY FUTURES

Marina Gorbis, *The Nature of the Future: Dispatches from the Socialstructured World*, Free Press, 2013.

Jerry Kaplan, *Humans Need Not Apply: A Guide to Work and Wealth in the Age of Artificial Intelligence*, Yale University Press, 2015.

John Markoff, *Machines of Loving Grace: The Quest for Common Ground Between Humans and Robots*, Ecco, 2015.

Alec Ross, *The Industries of the Future*, Simon and Schuster, 2016 (Chapter One: "Here Come the Robots").

