

LANDSCAPE OF CAREGIVING INNOVATIONS

FINDINGS AND RECOMMENDATIONS EXECUTIVE SUMMARY

"Family caregivers are interfacing with a fundamentally broken and disintegrated governmental system that is central to the financing of a lot of the care delivery system."

- Excerpt from CEO Roundtable

"It's hard to sell things to families, when every family is literally creating an entire delivery system, all by themselves, over and over again."

- Excerpt from CEO Roundtable

"My sister and I spent weeks researching different types of resources and options for our father. It would be great if there was a central resource to navigate this."

- Excerpt from Caregiver Interviews

LANDSCAPE OF CAREGIVING INNOVATIONS FINDINGS AND RECOMMENDATIONS

Executive Summary

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Susan Golden, Sc.D.

Director dciX, Stanford Distinguished Careers Institute

and

The dciX Caregiving Innovations Group

Susan Alexander '19

Susan Calandra '19

Nancy Carlson '19

Mark Clapper, MD '18

Michael Costa '17

Mimi Dunne, MD '19

Jeanine English '18 Jack

Keene, MD '19 Carol

Schrader '19

Eric Schrader '19

Steve Welker '19

Introduction

For individuals who take on the responsibility of caring for another person due to illness, disability, or declining abilities, it can often be challenging, lonely, costly, and exhausting. As the U.S. continues to address the impact of the unprecedented situation of COVID -19 on caregiving, the need to recognize and support family caregivers as the cornerstone of society has become even more important.

Today, more than one in five Americans (21.3%) are caregivers, defined as having provided care to an adult at some time in the past 12 months or a child with special needs. This totals an estimated 53 million adults in the United States, nearly ten million more caregivers since 2015. The [Caregiving in the US 2020¹](#) report issued by AARP and the National Alliance for Caregiving highlights that nearly 48 million unpaid caregivers are caring for someone over the age of 18.

The support needed by older adults and their family caregivers stems from several important sources:

1) Innovative companies with products and services benefitting care recipients; 2) Employers who provide benefits and assistance in recognition of the caregiving challenges faced by their employees; 3) Public sector medical reimbursement and coverage programs (e.g. Medicare, Medicaid, and Medicare Advantage); and 4) State and federal policies that address caregiving needs by providing financial incentives to all stakeholders.

Each of these is addressed in the Landscape of Caregiving Innovations report, along with an analysis of the state of innovations for caregiving for older adults. The report is divided into five sections:

- I. Understanding the magnitude of the challenge in family caregiving for older adults.
- II. Mapping the pain points and challenges encountered by unpaid family caregivers.
- III. The map of types of caregiving needs and solutions that are currently being developed.
- IV. Assessment of the innovation journey and challenges startups and founders are facing.
- V. Initiatives that could promote solutions that will assist families who care for older adults.

The Stanford dcix Caregiving Innovations Group assembled databases which include companies focused on solutions for caregiver challenges; reviewed and interviewed dozens of companies about their experiences in starting and growing their companies; identified and analyzed the barriers that companies face and their ability to scale and reach the caregivers and recipients who would benefit from their products and services; and interviewed caregivers to learn more about the obstacles they face.

In collaboration with Aging 2.0 [The Collective](#), we also held a Roundtable with leading CEOs in March 2021 to identify the barriers they collectively face and their recommendations to address them. We also evaluated the amount of capital invested in the past decade, and identified market needs and gaps that would benefit from further innovation and investment support.

The Landscape Report concludes with a key recommendation for moving forward and proposals for solutions: *The need for caregiving infrastructure to assist families, businesses, providers, insurers, and*

¹ Jr., Steven May. "Caregiving in the Us 2020." *The National Alliance for Caregiving*, 11 May 2020, www.caregiving.org/caregiving-in-the-us-2020/.

government to support the needs of the growing number of adults who will need care at some point in their life journey. To address the barriers that care recipients and innovators face, we envision the establishment of a Caregiving Hub and Innovations Marketplace to provide access to needed services and products.

The Landscape review is intended to serve as a guide for new entrepreneurs, innovators, and investors. The [full report](#) provides greater detail and an analysis of the data and information we reviewed on innovations and contains a series of appendices with resources and references. The following highlights key findings for this first phase of the Landscape of Caregiving Innovations.

Magnitude of the Challenges

Key demographic findings include:

- The number of people ages 65 and older in the United States has increased steadily during the past century; growth has accelerated since 2011 when baby boomers first started to turn 65.
- Between 2020 and 2060, the number of older adults is projected to increase from 56.0 million to 94.7 million.
- The number of people ages 85 and older is projected to nearly triple from 6.7 million in 2020 to 19.0 million by 2060.
- 61% of family caregivers are also working; 47% of adults in their 40s-50s are caring for both a parent who is 65+ and a child. Family caregiving spans across all generations and are very heterogenous and diverse.

Financial Impact:

- Unpaid family caregivers deliver 34 billion hours of care to older adults in the U.S., valued at \$470 billion.
- 75% of family caregivers incur out of pocket costs with an average spend of \$7400 per year, and on average \$13,000 if they live one or more hours away.
- Of those who have paid work in addition to unpaid caregiving responsibilities, 37% report quitting their job or giving up hours and lose over \$300,000 in lifetime wages and retirement benefits.
- Women are three times as likely as men to quit their jobs to take care of a family member. The impact of COVID -19 increased the number of women who left the workforce to serve as an unpaid caregiver, forgoing salary and benefits.

Impact on Caregiver Health:

- 23% of Americans say caregiving has made their own health worse.
- There is a lower life expectancy for long-term caregivers - 40% feel emotionally stressed, with one in five reporting financial problems.
- The Covid-19 pandemic exacerbated the family caregiving crisis - 31% of unpaid caregivers for adults reported having seriously considered suicide in the 30 days before completing a CDC 2020 survey.

Challenges Faced by Caregivers and Recipients: The Information Journey

The Caregiving Journey often begins with an Information Journey. Resources and information about caregiving that are available are currently siloed, residing in dozens of different websites, newsletters,

resource centers, and local and national organizations. Although there are many excellent resources, knowing about them, and curating them, are two key challenges. Unlike caring for children, where there is a plethora of books and products to help as they enter ever-increasing new stages of independence, no such comprehensive literature or platform exists for caregiving at the other end of life, where dependence increases over time. It is common to go from one new health and caregiving crisis to another, usually with new medical needs and different types of support and care needed. The primarily unpaid caregivers are not trained to handle this progression, nor to find the answers to the many questions and tasks they will have.

Care Coordination Journey: Establishing a Care System

Each family caregiver, or ideally the family, often needs to establish a care system for their care recipient. This involves a significant amount of care coordination, as it can include a combination of services they may provide, as well as identifying paid and unpaid assistance. An essential component of this journey is to preserve the dignity and wishes of the care recipient. There are three key parts to the Care Coordination Journey:

- **Understanding the care recipient's needs**, including health, medical, and functional needs - albeit knowing that it will change often over time
- **Determining care providers** to address each need; and
- **Identifying payors** for the services, products, equipment, food and supplies needed

Special Impact of COVID -19 on the Caregiving Journey

The impact of the pandemic of COVID-19 added another dimension and complication to providing care. Caregivers were suddenly faced with the quandary of how to protect their care recipient from the disease, as well as themselves. For those who manage different caregiver assistance in home, this became, at times, impossible choices. The research on [Caregivers in Crisis](#)² by the Rosalynn Carter Institute for Caregivers, found that 83% experienced increased stress related to caregiving since the start of the pandemic. Those surveyed expressed a need for more support than they are getting related to five specific areas: Respite and day care; Financial assistance; Social interaction; Peer support and self-care; Clinical and in-home care service.

Mapping the Caregiving Innovations Landscape

Caregiving innovations encompass products and services to assist caregivers, care recipients, healthcare providers, and employers of caregivers. Our review indicates that, over the last decade, over 300 new companies (and those with a new focus on caregiving) have been established to serve the needs of family caregivers and care recipients. We think the following fourteen buckets that include multiple subdomains of caregiving, will be useful for assessing and promoting opportunities for innovations for the next five to ten years:















Care Coordination Platforms and Navigators



Caregiving Tools and Management

² "Caregivers in Crisis." *Rosalynn Carter Institute for Caregivers*, Rosalynn Carter Institute for Caregivers, Oct. 2020, www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf.

 Caregiver Quality of Life	 Financial Caregiving
 Cognitive Health	 Healthy Aging
 End of Life Care and Planning	 Safe Aging and Home Accessibility
 Housing Alternatives and Transportation	 Intergenerational Engagement
 Information Platforms and Digital Accessibility	 Social Well Being and Social Determinants of Health
 Insuretech	 Telehealth and Health Care in the Home

Understanding the Caregiving Customer and Distribution Channels

The United States does not have universal health insurance. Our healthcare system is a mix of public and private, for-profit, and non-profit insurance plans and health care providers. There is no universal coverage for long-term care services. Who then is the caregiving customer? As in much of health care, the customer is not always the end-user of the product or service, and the payor for the service or product is similarly not always the care recipient or caregiver.

Defining and understanding the payor, the customer acquisition strategy, and the channel challenges are critical to the success of any innovation that addresses the caregiving needs of older adults. While the end-user of all caregiving products and services is most often either the care recipient or the unpaid family caregiver, the payor may be one or more of the following: Health care plans; Medicare Advantage plans; Medicare and Medicaid Services; Employers and Benefit programs; the caregiver; the family; the care recipient; healthcare providers.

Perspectives from Innovators

To develop frameworks for solutions and recommendations for innovators, entrepreneurs, and policy makers, a Roundtable was convened in March 2021 with fifteen leading caregiving executives. The goal was to have a candid conversation about the challenges they face, discuss what they would recommend to future innovators, and identify support and solutions for the next-gen products and services. We asked a simple question: ***As a community who cares about supporting family caregivers, what can we do to help your business grow?***

Common Obstacles to Growth

These eight key pain points and obstacles that affect the industry of caregiving and their ability to grow and scale were identified by leaders of caregiving companies:

1. **Distribution Channels:** We are missing direct-to-consumer channels. People who are caregivers or receiving care are in different phases and stages of life; there is no obvious channel to reach them.
2. **Health System Design:** Family caregivers are often not part of health care teams, and this results in a lack of integration and data sharing, and limited whole person solutions.

3. **Market Awareness:** Family caregiving has traditionally not been seen as valuable, pushing the burden and costs on caregivers who are often women. Innovators may end up working on incorrect or non-essential problems.
4. **Market Maturity:** There is little or no data on impact or ROI. Such data is necessary for acceptance and payment. This deficit creates inertia and slows innovation and partnerships.
5. **Policy:** The lack of family leave and caregiver support legislation limits the growth in this area. Universal family leave and funding for family caregiving would increase business opportunities and ensure quality support to family caregivers.
6. **Funding and Availability of Capital:** Family caregiving is not well understood compared to other tech sectors and is not always seen as relevant for (young) entrepreneurs and investors.
7. **Product Mix:** Solutions can be complex and caregiving situations diverse, requiring personalized approaches. Without a way to understand both what is needed and what is available, families are left to create a care system and improvise answers. Needs can also be episodic with periods of stability punctuated by periods of crisis and changing needs, which can undermine subscription business models.
8. **Staffing:** There is currently insufficient supply for ever-increasing demand. Attracting and retaining talent is a key barrier. Finding front-line professional caregivers and care coordinators with expertise in managing complex, dynamic situations is challenging.

Moving Forward: The Future of Caregiving Solutions

We would all benefit from better infrastructure to support families and caregivers, as well as to support innovators. Consumers need personalized, curated, and timely information, insights on relevant products and services, as well as help navigating the complexities of care. Innovators need help connecting with the families who need their products and services, plus the ability to connect with other entrepreneurs, investors, and potential clinical and strategic collaborators (e.g. for efficacy validation and impact metrics).

We propose next steps should be examining the landscape, feasibility, and specifications of a marketplace (or marketplaces) to help both families and innovators, as well as engaging in necessary policy and educational campaigns to continue to raise the profile and importance of this topic among decision makers, families and voters. These include:

1. **Caregiving Information and Solutions Marketplace:** An investigation in to how best to provide personalized access to the many different excellent resources and curated sources of information based on a family's needs, diagnosis and stage of care. A key requirement is that this would be made available free to any caregiver, care recipient or family member.
2. **Caregiving Innovations Marketplace:** Developing the parameters of a Marketplace to include payors such as employers, providers, and startups and scaleups, where companies and organizations who have products, services and solutions are listed. Features of this marketplace should also include access to clinical trials, evaluation, impact metrics, strategic partnerships, collaborations and an investor platform (eg enabling crowdsourcing of ideas for innovation gaps and solutions).

3. **Policy and Narrative Initiatives:** The recent media coverage of the crisis in caregiving offers an opportunity to increase awareness in public forums and to support policy initiatives. A national education campaign on the value of caregivers and caregiving, would enhance support for the implementation of local, state, and federal policy initiatives.

We believe there is an important role for business to play in creating public-private partnerships to help build a caregiving infrastructure for the millions of families who care for older adults. While there has been significant growth in investment in care for older adults by early-stage investors over the past ten years - up from \$39 million in 2011 to \$1.14 billion in 2020³ - we see a need to further educate investors about the opportunities for supporting caregiving innovations, about the broader marketplace opportunities, and how best to support entrepreneurs committed to developing solutions for the 53 million unpaid caregivers and their recipients.

An infusion of public funding and new policies will also alter the landscape of caregiving innovations. We eagerly await the implementation of the Biden administration's proposal to fund human infrastructure to enable more care at home than at institutions and hospitals⁴, and increased access to Home and Community-Based Services⁵. The expansion of state tax credits and financial incentives such as those being implemented in Washington State through the proposed Credit for Caring Act of 2021⁶ would also assist and impact caregivers. These policy and funding innovations may translate into economic incentives that innovators can utilize to design better solutions.

This is a dynamic and growing field, and this report will be updated annually to share new initiatives and perspectives. Our next focus will be to scope and develop requirements for the marketplace and narratives ideas above, and address some of the barriers that are commonly faced by both caregivers and innovators. We hope to serve as a catalyst to spark ideas and ignite a passionate, mission-driven community of like-minded innovators to help turn these concepts into a reality with significant market impact.

We see a great deal of momentum now in this country, in large part due to the leadership of Pivotal Ventures, to help millions of families provide care with dignity and respect to those they love. We thank Pivotal Ventures for their support of this work.

³ Glasner, Joanna. "Funding Surges for Startups Serving Older Adults." *Crunchbase News*, Crunchbase News, 4 June 2021, news.crunchbase.com/news/eldercare-senior-home-care-startups-funding/.

⁴ "Coverage of Biden Administration Proposal to Expand Home- and Community-Based Services." *ACL Administration for Community Living*, 12 Apr. 2021, acl.gov/news-and-events/news/coverage-biden-administration-proposal-expand-home-and-community-based-0.

⁵ "Home & Community Based Services." *Medicaid*, www.medicaid.gov/medicaid/home-community-based-services/index.html.

⁶ *Congress*, www.congress.gov/.