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 United States continues to address the unprecedented impact of Covid-19 on caregiving, the need to recognize and support family caregivers as the cornerstone of society has become even more urgent.

Today, more than one in five Americans (21.3%) are caregivers, defined as having provided care to an adult at some point in the past 12 months or to a child with special needs. According to the AARP and the National Alliance for Caregiving, in 2020 there were nearly 48 million unpaid caregivers in the United States, a number that swelled further during the pandemic.

Despite the enormous and growing needs of unpaid caregivers, there is no comprehensive infrastructure in the United States to support them. Becoming a family caregiver is a complex journey that often requires obtaining and evaluating vast amounts of information for which there is no central clearinghouse, improvising and coordinating a care system for their loved one, identifying who will pay for the needed services, and adjusting to the changing needs of the care recipient. They do all of this while also working (61%), caring for their own children (47%), and dealing with the health, social, and financial consequences of managing and providing care (80%).

The goal of the Stanford Distinguished Careers Institute’s dciX-Caregiving Innovations Project, in partnership with Pivotal Ventures, is to catalyze change in the underserved market for adult caregiving. We set out to evaluate the current state of products and services to support caregivers and care recipients, and to identify ways to make the journey less fraught and overwhelming. We hope this project will advance the efforts of the many organizations and individuals working to spur creation of an infrastructure for caregiving in the U.S., on which so much of our economy rests.
Part I of our review was released in 2021. It includes an analysis of the caregiver journey, the identification of barriers to scaling innovations and existing resources, and recommendations for solutions to move care forward.

Part II focuses on the creation of an infrastructure to help caregivers of older adults. It includes our blueprint for a new Care Connector platform that would be available to all caregivers for free and would serve as a hub for information and resources and a marketplace for solution providers.

It is our belief that the complex challenges we identify can best be addressed by soliciting, iterating, and optimizing ideas from all who have an interest in this critically underserved market. We hope this report will catalyze fresh thinking and ignite a passionate, mission-driven community of innovators to transform these ideas into resources, services, and businesses with real market impact. We offer our findings as a reference tool for all interested parties to use in developing a functioning care system.

**KEY FACTS**

**Demand Is Soaring**
- Between 2020 and 2060, the number of adults age 65 and older is projected to increase from 56.0 million to 94.7 million.
- The number of people age 85 and older is projected to nearly triple from 6.7 million in 2020 to 19.0 million by 2060.
- Nearly half of adults in their 40s and 50s care for a parent and a child, and 61% of family caregivers also have jobs.

**Caregivers Are Suffering**
- 40% of caregivers feel stressed, with one in five reporting financial problems. In a survey, 31% report having considered suicide.
- 23% say caregiving has made their own health worse. Long-term caregivers have lower life expectancy.
- Covid-19 greatly exacerbated the family caregiving crisis, with 83% reporting increased stress since the pandemic began.

**Financial Burdens Cut Deep**
- Unpaid family caregivers deliver 34 billion hours of care to older adults in the U.S. That care is valued at $470 billion.
- 75% of family caregivers incur out-of-pocket costs, averaging $7,400 per year if they live nearby, and far more if they don’t.
- 37% of those who are employed quit their job or give up hours, resulting in a $300,000 loss in lifetime wages and benefits.
- Women are three times as likely as men to quit their jobs to care for an elderly family member.

**Who Is the Customer?**
- Defining and understanding the payor, the customer-acquisition strategy, and the channel challenges are critical to success in this market.
- The U.S. healthcare system is complex and fragmented, with little coverage for long-term care.
- While the service end user is typically the care recipient or caregiver, the payor may be healthcare plans, employee benefit programs, or healthcare providers.
PART I: CAREGIVER JOURNEY AND PERSPECTIVES FROM INNOVATORS

The Information Journey Is Complex

Although there are many excellent information resources available for caregivers and care recipients, they tend to be siloed in dozens of websites, newsletters, and resource centers maintained by local and national organizations, and they are difficult for the uninitiated caregiver to locate and interpret. In addition, it is common to go from one new health and caregiving crisis to another, each bringing new and escalating medical, support, and care needs. Unpaid or minimally trained caregivers are ill-equipped to handle this progression and find answers to their questions.

Establishing a Care System Is a Critical Early Step

Families need to establish a care system for an adult in need. This involves a lot of coordination, as it can include a combination of services as well as enlisting paid and unpaid assistance. An essential component of this journey is preserving the wishes and dignity of the care recipient. Coordinating care involves three key steps:

• Understanding the care recipient’s health, medical, and functional needs, which will change often over time
• Selecting care providers to address each need
• Identifying payors for the services, products, equipment, food, and supplies needed
A Map of the Caregiving Innovations Landscape

Since 2010, more than 300 new companies have been established to serve the needs of family caregivers and care recipients, focused in one or more of the following areas.

Perspectives From Innovators Are Crucial

To develop recommendations for innovators, entrepreneurs, and policymakers, we convened a roundtable with 15 leading caregiving executives in March 2021. The goal was to have a candid conversation about the challenges they face and to gather their insights for future innovators. Roundtable participants identified the following pain points and obstacles to innovation, growth, and ability to scale:

**Distribution Channels:** We are missing direct-to-consumer channels. Caregivers are in different stages of life, and there is no obvious channel to reach them.

**Health System Design:** Family caregivers are often not part of healthcare teams. This results in poor integration and data sharing and a lack of whole-person solutions.

**Market Awareness:** Companies lack information on family needs. As a result, innovators may end up working on incorrect or non-essential problems.

**Market Maturity:** There is little or no data on impact or ROI. Such data is necessary for acceptance and payment. This deficit slows innovation.

**Policy:** Legislation for universal family leave and funding for family caregiving would increase business opportunities and ensure quality support to caregivers.

**Capital:** Family caregiving is not front-of-mind for many investors and entrepreneurs, who may not grasp the size of the potential market.

**Product Mix:** Caregiving situations are diverse, requiring personalized approaches. Episodic demand undermines subscription business models.

**Staffing:** Finding front-line professional caregivers and care coordinators with expertise in managing complex, dynamic situations is challenging.
PART II: SOLUTIONS LANDSCAPE

Creating a Blueprint for a Care Connector

In the second phase of the Landscape of Caregiving Innovations project, we propose a new approach to address the pain points identified in Part I of our report. A key goal was to cut through the confusing array of resources and care options that families struggle to navigate, and contribute to the design of an accessible, organized infrastructure to support families and caregivers.

We propose that this infrastructure take the form of a Care Connector, a one-stop platform or hub consolidating resources and connecting consumers, solution providers, and innovators through a targeted and efficient matching mechanism. Consumers need personalized, curated, and timely information, insights into relevant products and services, and assistance navigating the complexities of care and reimbursement. Similarly, innovators need help connecting with individuals and their families who would benefit from their products and services, the ability to connect with potential clinical and strategic collaborators who could provide validation and impact metrics, and greater access to funding.

Care Connector

We evaluated the many pieces of the existing information and solutions puzzle, and we identified seven components as essential for a blueprint for a national information and solutions platform and marketplace:
Awareness: A national information campaign will be needed, as well as local efforts, to help people identify as “caregivers” and introduce them to the Care Connector platform. This will help to populate the “funnel.”

Discovery: Caregivers may be directed to Care Connector by an awareness campaign or via links from other resources. For those without digital access, facilitators would be available by phone.

Assessment: Separate assessments would be done for the needs of both the caregiver and recipient. There would also be a financial assessment to understand any insurance or employer benefits available to the family.

Matchmaking: Assessments result in curated information and solutions. These are then tendered to solution providers and partners, who match their capabilities and respond with offers.

Conversion: Caregiver understands the options, chooses among the solutions generated, and engages with partner services. Providers may offer “free” service for every generated lead to their company.

Fulfillment: Solution providers and partners deliver services to the care recipient or caregiver, and payment mechanisms are identified. Reassessments will be necessary as the care recipient’s needs change.

Feedback: Recipients and partners will provide feedback on quality, satisfaction, and impact of the Care Connector platform and services. This information will guide ongoing improvements in the platform.

This blueprint serves as an open-source innovation tool, with the hope that others will contribute and revise it on behalf of caregivers, care recipients, and families everywhere. We want all stakeholders to review and contribute to these concepts, to help create a viable, effective, ethical, and trustworthy platform for caregivers to get the information and solutions they need, and to help spur further innovation, investment, and policy to support them.

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. All of us involved in the dciX Caregiving Innovations Project thank Pivotal Ventures for their support of this work and their commitment to caregivers.

Please send your feedback and ideas to: sgolden2@stanford.edu