

THIS WEEK IN CAREGIVING



January 27, 2021



CAREGIVING IN THE NEWS

Reimagining the Future How Together Industry and Regulators Can Change the Clinical Trial Paradigm

"We hear from patients that participating in clinical trials places enormous demands on them. For many, participation could take up to a week out of their life as well as their caregivers. Considering that patients will have to do this a few times a year, it places a huge burden on them and their family," says Peter Bergethon, Vice President and Head of Digital and Quantitative Medicine at Biogen.

... A digital trial recognizes these components and decentralizes several activities thus removing the burden of travel on the patient and their families. Additionally, doing things remotely could potentially mean reaching more patients, something that would be particularly important with rare diseases. Ultimately this could mean getting to a potential treatment faster.

'Decentralizing clinical trials and moving to digital is by no means a novel idea. As an industry we have been using digital technologies to collect data for some time. And we have made some headway, especially in clinic,' says Peter."

From: Biogen

[SEE MORE](#)



For more information on digital clinical trials, check out the Research and Resources section at the end of this newsletter.

Caring for Latino Patients and Families During COVID-19

"As we approach the one-year anniversary of the COVID-19 pandemic in the United States, Latinos – also referred to as Hispanic or Latinx populations – remain among the hardest hit. Since some of the earliest outbreaks in food production workplaces, Latinos

Prioritizing Family Caregivers for the COVID Vaccine

This op-ed was written by a family caregiver, Maggie Ornstein.

"Family caregivers are direct care workers. We are essential workers. We are unpaid home care workers doing the same job as hospital and nursing home

have comprised 33% of COVID-19 cases as of December 2020 (despite accounting for 18.5% of the population); been hospitalized at 4x the rate of White Americans; and experienced greater case outbreak severity and death rates in nursing homes."

Read on to understand this disproportionate impact.

From: CAPC Blog | January 8, 2021

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staff, but without pay, labor protections or other benefits. If we aren't protected, many of those we care for could end up in nursing homes, where 40 percent of COVID-19 deaths nationwide have occurred and where care is costly, placing an additional and intense burden on an already strained health care system. Protecting family caregivers, along with those they care for, is good public health.

From: CityLimits | January 20, 2021

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CAREGIVING FACT OF THE WEEK

Mental Illness Caregiving

As many as 27 percent of caregivers of adults over the age of 18 are providing care to an adult with an emotional or mental health issue (according to research from NAC and AARP's **Caregiving in the U.S. 2020**). As some have said, mental illness is a disease that affects the whole family. Family caregivers feel the impact of the disease as they struggle to care for their loved ones and to bridge health care systems, mental health providers, and community supports.

In February 2016, The National Alliance for Caregiving, in partnership with **Mental Health America** and the **National Alliance on Mental Illness** released a study on the obstacles and opportunities facing caregivers of adults with mental illness. The study, **On Pins & Needles: Caregivers of Adults with Mental Illness**, identified startling inadequacies in the U.S. health care system in meeting the needs of families who manage moderate-to-serious mental illness.

02: Economic Impact of Mental Health Caregiving

Introduction

Approximately half of family caregivers in a national study of mental health caregivers¹⁰ reported that their care recipient relied on family and friends for financial support. Intricately linked to financial support were plans for the future. According to caregivers in the study, 64% reported that their adult child was financially dependent on friends and family. When it came to future plans, only 32% had financial arrangements for future care of their child.¹¹

The economic impact of caring for a care recipient with mental illness can be devastating: the time invested in helping someone attend doctors' appointments, helping with medications, and missing

work. All of these issues require financial investment. **Figure 25** (see below) from the report *On Pins & Needles* provides an interesting backdrop to this discussion.

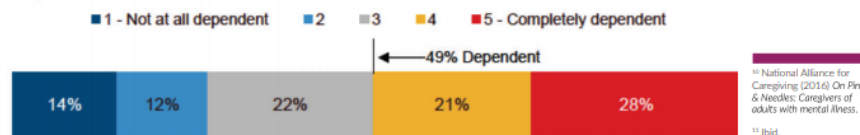
Background: The Economic Impact of Mental Illness on Caregivers

According to the World Health Organization (WHO), mental illnesses are the leading causes of disability worldwide, accounting for 37% of healthy years lost from non-communicable diseases. The new report estimates the global cost of mental illness at nearly \$2.5 trillion (T) (two-thirds in indirect costs) in 2010, with a projected increase to over \$6T by 2030. What does \$2.5T or \$6T mean? The entire global health spending in 2009 was \$5.1T. The annual

Figure 25: Care Recipient's Financial Dependence

Q43: How financially dependent is/was your [relation] on his/her family or friends?

(n=1,601)



To support caregivers of individuals managing a mental illness, the National Alliance for Caregiving and the National Alliance on Mental Illness developed **Circle of Care: A Guidebook for Mental Health Caregivers**. The guidebook emerged from the national study on mental health caregiving and was designed to guide unpaid friends, family, and neighbors who care for someone with a mental health condition. The fact sheets are intended to assist these caregivers with finding help for the specific challenges identified in the On Pins and Needles study.

Click the red link below to check out the guidebook.

[LEARN MORE](#)



EVENTS & OPPORTUNITIES

UPCOMING WEBINARS

What's Next Longevity Innovation Summit

March 1, 2021 | Washington, D.C. | Virtual



Position your company as a leader in the longevity market, make connections with leaders in this space, and gain a unique perspective on how five generations are impacted by an aging population.

[REGISTER](#)



PAST EVENTS



Challenges of Aging During COVID-19: Long-Term Care, Vaccination, and Isolation

January 15, 2021 | Online

Since the beginning of the pandemic, the danger COVID-19 poses to older adults and people living in long-term care facilities has been of great concern. COVID-19 has claimed the lives of more than **125,000** long-term care residents and staff and **8 out of 10** COVID-19 deaths reported have been among adults aged 65 and older. Now with two authorized vaccines and the **CDC** recommendation of older adults for early vaccine access, there is hope, but there are still challenges with distribution. It is also necessary to address the pandemic's mental health impact on older adults, particularly loneliness and isolation. While older adults have reported **less loneliness** than their younger counterparts during the pandemic, about **one in four** report anxiety or depression due to the pandemic. Speakers discussed:

- Overview of COVID-19's challenges to long-term care and the future implications for nursing homes
- Vaccination and vaccine distribution challenges for older adults
- A health plan's efforts to address pandemic isolation and loneliness

[ACCESS THE PRESENTATION](#)



Early Lessons from the COVID-19 Vaccine Rollout to High Priority Populations

January 14, 2021 | Online

KFF held an interactive web event on Thursday, January 14 to provide the latest data on COVID-19 cases and deaths in long-term care facilities and examine how the effort to vaccinate residents and staff in long-term care settings is going, challenges experienced so far, and opportunities for improvement.

[WATCH THE RECORDING](#)



[CALL FOR APPLICATIONS](#)



Deadline: April 15, 2021

Candidates with a strong commitment to health and aging issues, leadership potential, and interest in aging-relevant policy work are invited to join the next class of Health and Aging Policy Fellows (2021-2022).

The Health and Aging Policy Fellows Program continues to make great strides in advancing policy with creative solutions in the context of COVID-19.

APPLY



ARCH Seeking to Recognize Respite Innovation & Quality

Deadline: March 1, 2021

If your respite service addresses critical respite needs for any population in your community and can demonstrate innovation and quality worthy of replication, you can apply for recognition as an ARCH Innovative and Exemplary Respite Service.

If selected, your services will be recognized as a potential model for replication!

APPLY



U.S. NAM Catalyst Award Competition Round 2 (2021)

Deadline: March 8, 2021

As part of the Healthy Longevity Global Competition, the U.S. National Academy of Medicine (“NAM”), with support from Johnson & Johnson Innovation, will issue up to 24 Catalyst Awards per year, in three annual rounds (i.e., in 2020, 2021, and 2022). Each Catalyst Award includes a \$50,000 cash prize as well as travel costs to attend an annual Innovator Summit.

There will be one application period per year. The current request for applications is for Round 2 of the NAM Catalyst Awards. The application period opens on January 25, 2021 and closes on March 8, 2021.

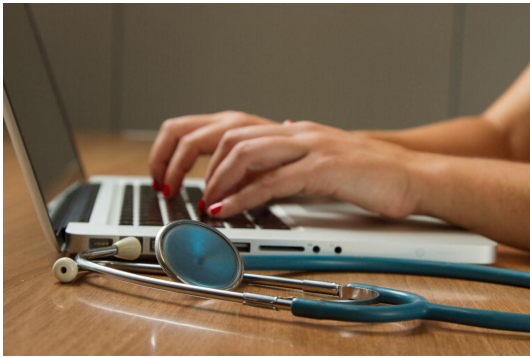
Catalyst Awards will reward bold, new, potentially transformative ideas to improve the physical, mental, or social well-being and health of people as they age, in a measurable and equitable way.

Click the red link below to learn more and apply.

APPLY



Biogen: Transforming the Regulatory Landscape for Digital Health Technologies in Drug Development



This white paper from **Biogen** summarizes the value of digital health technologies (DHTs) in drug development and proposes several solutions to achieving a modernized regulatory approach that harnesses the full potential of these innovative technologies.

According to this paper, DHTs are effective in increasing access to clinical trials through cost reduction and improvement in caregiver and patient convenience.

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