

# **Executive Office of Elder Affairs**

Massachusetts Family Caregiver Support Program (MFCSP) Newsletter

May 2019

# **CAREGIVING IN THE NEWS**

## Sandra Day O'Connor and Alzheimer's: A Personal Story

This *Forbes* article **shines a light on Justice Sandra Day O'Connor's personal story**, first as a caregiver for her husband living with Alzheimer's and then as someone living with a dementia diagnosis.

## **Our Health Care System Fails Family Caregivers**

In this *Boston Globe* op-ed by Ellen Bender, she describes the **difficulty caring for her husband when he was discharged from the hospital**. According to Bender, more work is needed to prepare family caregivers during the discharge process and provide caregivers with access to care providers.

## Few Family Caregivers Get Formal Training

This article by *Reuters* describes a study done on survey data from almost 2,000 family caregivers that demonstrates that **less than 1 in 10 caregivers receive training** to help care for their loved ones. Furthermore, family caregivers often report feeling unprepared for their caregiving role and responsibilities.

# **RESEARCH AND POLICY UPDATES**

## Washington State Passed Long-Term Care Trust Act

Washington state lawmakers recently passed the <u>Long-Term Care Trust Act</u>, which provides **long-term care and caregiver support** to eligible individuals from a state trust fund. One of the goals of the legislation is to **help individuals avoid spending down** to qualify for Medicaid long-term care.

#### Why Are Family Caregiving Questions Missing From the 2020 Census?

While the United States 2020 Census will include questions regarding grandparents raising grandchildren, it **will not include questions related to caring for an adult family member or disabled child**. This *Next Avenue* piece discusses the potential implications.

#### Hawaii's Kupuna Caregivers Program Helps Caregivers Stay Employed

Iris Yafuso-Toguchi's caregiving experience, featured in the *Honolulu Civil Beat*, describes how the state's **Kupuna Caregivers Program** provides much needed assistance to help her care for her mother who is living with Alzheimer's. The current program **provides \$70 a day to eligible caregivers**.

#### Home Alone Revisited: Family Caregivers Providing Complex Care

AARP's Public Policy Institute recently published a follow-up report to the landmark <u>Home Alone study</u>, which was the first national look at how family caregivers are managing medical and nursing tasks. **The updated report includes five findings**, ranging from the diversity of family caregivers to the elevated role of health systems supporting them.

# IMPORTANT PROGRAM ANNOUNCEMENTS & REMINDERS

Thank you to everyone who has already provided input into the statewide **Operations Manual** and **Caregiver Guide**. We greatly appreciate your perspective and willingness to share materials from each of your programs!



May is Older Americans Month! The theme for this year - Connect, Create, Contribute – celebrates older adults and the role they play in our communities. Older residents play a key role in the vitality of our neighborhoods, networks, and lives. Please visit ACL's website for more information and ideas for

# THIS MONTH'S CAREGIVING MANTRA

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"To love a person is to see all of their magic, and to remind them of it when they have forgotten."

Author Unknown

## **MONTHLY SPOTLIGHT**

Baker-Polito Administration Launches New Initiative to Help Grandparents Caring for Grandchildren with Access to Early Education



On May 8, the Baker-Polito Administration <u>announced a new</u> <u>initiative</u> during a meeting for the **Commission on the Status of Grandparents Raising Grandchildren**. The Commission on the Status of Grandparents Raising Grandchildren was created in 2008. It is estimated that over **10,400 children** in Massachusetts living without their biological parent are being raised by their grandparents or relative caregivers.

## The new initiative will **improve access** to high-quality early learning

opportunities for low-income children being raised by relative caregivers. Early learning programs support young children's healthy development and also serve as an employment support for families by providing child care when they are working.

The initiative, launched jointly by the **Department of Transitional** Assistance (DTA) and Department of Early Education and Care (EEC), will help approximately 3,800 caregivers access subsidized child care if they are working. Through the partnership, DTA can now authorize child care for relative caregivers so the child can attend a high-quality early learning program through funding from EEC. Until now, DTA was only able to provide economic assistance for this population and interested families may have been placed on a waiting list for child care financial assistance.

For more information on the Commission on the Status of Grandparents Raising Grandchildren, please visit their <u>website</u>!

# **HELPFUL RESOURCES**

#### **Caregiving and Dementia Series: Understanding Responsive Behaviors**

This short two-part webinar series (<u>Part 1</u>, <u>Part 2</u>) was created by The National Center for Montessori and Aging at Crossway Community, in partnership with Montgomery County Maryland's Caregiver Support Program. The series discusses the **importance of purposeful engagement for people living with dementia** and provides guidance for caregivers.

#### New from Novartis and NAC: The Caregiver's Guidebook

Novartis, in partnership with the National Alliance for Caregiving, has created The Caregiver's Guidebook, to **help caregivers gain insight into what to expect along the way**, as well as checklists and worksheets. Novartis also released the *forCare* **mobile app for iPhone**, which equips caregivers with information and tools.

#### Web Platforms Help Match Caregivers to Technology Solutions

<u>Alz You Need</u> and the new <u>Aging2.0 Caregiving Collective</u> are two examples of web platforms that aim to **match caregivers with innovative solutions that are tailored to their caregiving needs**. Both are free to use and help consumers better understand the constantly evolving market.

#### Caregiving MetroWest: How to Choose a Support Group

Caregiving MetroWest's <u>Skill Building for Caregivers</u> webpage includes a plethora of "how-to" resources, including **advice on how to choose a support group**. The webpage includes **questions to ask** and reminds caregivers that it is okay if the first group you try is not the right match!

# **EVENTS AND WEBINARS**

#### <u>Grandparents Raising Grandchildren: Statewide Community Workshops</u> (May 20 – Harwich, May 28 – New Bedford)

The Commission on the Status of Grandparents Raising Grandchildren is convening workshops this spring to benefit family caregivers. **Each workshop is three hours long and includes a guest speaker and panel of representatives from agencies** who work with grandparents raising grandchildren. **Registration is required.** 

## **Experienced Dementia Caregivers Share their Stories and Best Lessons** (May 21, 5:30-7:00 PM in O'Keefe Auditorium, Massachusetts General Hospital Transformation Center)

As part of their **Conversations with Caregivers** series, Massachusetts General Hospital's Dementia Care Collaborative is hosting three experienced dementia caregivers to share their stories and experiences. Admission is free and seating is limited. **RSVP to 617-724-0406**.

# Free Community Lecture Series for Caregivers of Individuals Living with Alzheimer's or Dementia

(May 23, June 5 at 6:30-8:00 PM in Shipley Auditorium, 2<sup>nd</sup> Floor Newton-Wellesley Hospital – No Registration Required)

Newton-Wellesley Hospital and Good Shephard Community Care are partnering to offer a three-part, **free community lecture series** to provide education and support for caregivers. Upcoming lectures covering **safety and independence, advance care planning, and decision-making capacity** are on May 23 and June 5 at Newton-Wellesley Hospital.