



The John A. Hartford  
Foundation

RAISE FAMILY CARE ADVISORY COUNCIL MEETING, MAY 20 – 21, 2020

## MEETING SUMMARY

### DAY 1

The first Day of the FCAC meeting began with a call to order and opening remarks from Lance Robertson, Administrator and Assistant Secretary for Aging. During his opening remarks, Administrator Robertson expressed gratitude for the hard work the RAISE council has dedicated towards addressing the challenges faced by caregivers across the nation as well as the development of a National Caregiver Strategy and the initial report to Congress. Administrator Robertson touched on topics such as the work that ACL has been doing in response to the COVID19 pandemic. In response to the pandemic, ACL was able to disburse an additional 1.2 billion of aid to states, with thanks to the supplemental grants received through the Family First Act and CARES Act. Of the supplemental funding disbursed, ACL put 60 percent towards fighting food disparities through its meals program. The Cares Act program has become more diverse, now including initiatives that support family caregivers. ACL has provided 100 million dollars to states to help strengthen the Caregivers Support Program nationwide. In an effort to expand resources, ACL has placed nearly 30 resourceful documents on the [Acl.gov](https://acl.gov) website, which provides guidance and technical assistance to everyone including the public during the pandemic.

Administrator Robertson also welcomed Sarah Markel, the newest federal member of the team who has a background in writing and journalism. Sarah will be doing some significant writing for the Council's work. Also with the federal government recently holding its Public Service Recognition week, Administrator Robertson encouraged the audience to take time to celebrate federal employees and all the hard work that they continue to do under the present circumstances. The meeting held today will cover the issues faced in the family caregiving community and

some insight into the Council's proposed resolutions, which will be addressed in the initial report to Congress and the National Caregiver Strategy.

The moderator, Greg Link who is also the Federal Designated Officer for the RAISE Council moved the meeting forward by briefly going over the meeting Agenda followed by roll call of the council. Greg noted that this meeting was developed in collaboration with the National Academy for State and Health Policy (NASHP) based on the subcommittee's work in March and April. He also mentioned that May is Older Americans month.

### **Project Updates**

The meeting continued with project updates from ACL, John A. Hartford, and NASHP. Two major updates from ACL were regarding the published report on the [Progress Toward a National Strategy to Support Family Caregivers](#) and Administrator Robertson's blog [ACL Supports Family Caregiving During the COVID-19 Pandemic Response](#) which was also referenced by Secretary Azar in a HHS blog.

### **The National Academy for State Health Policy**

Council members actively engaged in a discussion regarding the characteristics for recruiting caregiver focus groups in collaboration with NASHP and Focal Point Global as partners. Focus groups are scheduled to meet in groups of six people per session for twelve sessions beginning on May 28, and then June 2 – 4. It was agreed that listening sessions could be bigger in number including stakeholders that will eventually add more voices to the discussion.

Members also talked about the need to take bold steps and not back down from ensuring that financial impact of caregiving on families is carefully considered not only for the present, but also for future action. The moderator asked members with ideas/thoughts on how best to analyze the information obtained from the RFI to submit it to him or Wendy.

### **RFI Analysis and Presentation**

Pam Nadash of the University of Massachusetts (UMass) Boston, contracted by NASHP to conduct an in-depth review/analysis of the RFI responses, presented the

preliminary findings. The RFI received 1,613 responses. Of the number of respondents, 75% came from family caregivers, and there were no significant differences between identified priorities for family caregivers and individuals responding on behalf of an organization.

Among the top priorities are service planning, family centered care, and respite followed by financial issues/financial security. The responses represented a diverse group comprised of different ages, racial/ethnic backgrounds. The analysis included the single most important recommendation expressed by respondents: the need to pay family caregivers for the work they do, either through some form of tax credits, social security credits, etc. The presentation resulted in a robust conversation among members regarding some of the findings from the RFI submissions, and how best to utilize this information for the greater good. The presenter informed council members that information, discussions and recommendations from the upcoming focus groups and listening sessions will help the council recalibrate its focus in better addressing some of the most important issues facing family caregivers

### **Family Leave Presentation - AARP**

Members also listened to a presentation by Lynn Feinberg from the American Association of Retired Persons (AARP) which focused on the need for a comprehensive paid family leave for employees was discussed extensively by members as a win-win for everyone involved, and should be an issue deserving of an urgent national conversation, consideration, and legislation. She talked about the history of the first Family Leave Act (FMLA) enacted in 1993, and why family leave is important for American working families. The conversation shifted to examining the gaps that currently exist in the availability and use of Paid-Time-Off (PTO). The discussion considered two recent bills that went into effect on April 2, 2020, in response to COVID-19. The bills expire December 31, 2020. Members were introduced to state-by-state efforts that addresses the gaps as well as research based recommendations that could be worth their consideration as they struggle to find the most practical solution to this important issue.

## **DAY 2**

The second and last day of the FCAC full council meeting began with Administrator Robertson expressing his appreciation to two key partners of the council's work, The John A. Hartford Foundation (JAH) and the National Academy for State and Health Policy (NASHP), for their work in support of ACL and family caregivers. He informed members that of the \$1.2 billion ACL received, ACL will use \$100 million to strengthen the caregiver program, and that the plan is to share the outcomes of that support soon. He encouraged members to pay attention to the programs offered by ACL and to look at the recently published blog on Older Americans month.

The moderator and Federal Designated Officer Greg Link then did a roll call of the RAISE council members before diving into the Agenda and housekeeping items. He informed members that there would be a poll during the meeting to capture the council's preference of either a one-day or two-day full council meeting every month, versus a continuation of subcommittee meetings. Greg gave the council the option to meet via a combination of both subcommittee and full council meetings every month for the remainder of the year. He provided members a preview of the two important presentations they will be listening to during the remainder of the day on respite care and data gathering and research.

### **Respite Care**

Greg turned the meeting over to Jill Kagan, the Director of the ARCH National Respite Network and Resource Center, who developed a presentation on respite care and how it affects caregivers. The discussion began with defining respite as "the actual plan or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers for caring for that child or adult". Greg informed the council that this definition is included in the Lifespan Respite Care act. Members listened to the challenges family caregivers face when attempting to access respite care, the financial and emotional toll involved, what is missing, and finally, some practical commonsense recommendations including best practices, and non-governmental partnerships that are working to address the gaps.

### **Data and research Presentation**

Dr. Scott Beach, Director of the Survey Research Program at UCSUR/University of Pittsburgh, and Joe Caldwell, Director of the Community Living Policy Center

at the Lurie Institute for Disability Policy, Brandeis University, gave a presentation on data and research including the major gaps and the improvements needed to improve caregiver access to resources. They introduced data gathering and research statistics that could lead the way to new pathways for lasting changes in family caregiving.

### **Working Session: National Strategy Driver Diagram**

Over several months, the council worked on the national strategy driver diagram as subcommittees and for the first time they were able to come together as one to review and provide feedback on the latest iteration of the driver diagram.

### **Wrap Up and Next Steps**

- Based on the poll results, ACL will schedule a full council meeting in July.
- ACL will send calendar invites to the council for the upcoming virtual NASHP Faculty Listening sessions;
- The council was encouraged to further review the Driver Diagram to submit additional feedback on revisions, and ideas around actions steps pertaining to the five goals that will help achieve the overall aim of moving collaboratively towards a National Caregiver Strategy.