

# Innovations in Workforce Education for Family Caregiving

Virtual Summit

*September 16-17, 2020*

# INNOVATIONS IN WORKFORCE EDUCATION FOR FAMILY CAREGIVING

## Summit Summary

September 16-17, 2020

In 1979, Ethel Shanas published a ground-breaking report debunking the myth that older adults in the United States were abandoned by their families (Shanas, 1979). Since then, thousands of research studies on the important social phenomenon of family care for frail older adults have been published. And despite all we have learned, family caregivers remain the invisible members of the healthcare team.

On September 16 and 17, 2020, the Family Caregiving Institute at the Betty Irene Moore School of Nursing at UC Davis convened a group of over 80 diverse professionals to showcase and discuss educational programs designed to help current and future generations of healthcare workers to better support family caregivers and older adults. The meeting consisted of plenary, panel, and small group discussions. The summit was originally planned as an in-person event, to be held on the UC Davis Health campus in Sacramento, California. However, COVID-19 required a change to a virtual event, hosted on Zoom Video Communications, Inc. (Zoom). This report provides an overview of the sessions and group discussions. Please reach out to the primary authors to learn more about the presentations shared at the summit.

### Day 1: September 16, 2020

#### Opening Remarks

The summit launched with opening remarks and a review of the summit's goals from **Terri Harvath, PhD, RN, FAAN, FGSA**, Senior Director for Strategic Initiatives, Clinical Professor, and Director of the Family Caregiving Institute. In the session, "Innovations in Workforce Education: A Call to Action," Dr. Harvath highlighted the need for an increase in the quality and quantity of clinical education initiatives that effectively support family caregivers. She

also spoke about the ways in which the pandemic has shed light on the critical role of family caregivers, who have been increasingly relied upon to do more, in an increasingly isolated environment, while being under additional stress.

## Keynote Address

A keynote address on “Transforming Workforce Development to Address Changing Caregiving Needs” was delivered by **Joan Weiss, Ph.D., R.N., C.R.N.P., F.A.A.N.**, Senior Advisor in the Division of Medicine and Dentistry at the Department of Health and Human Services (DHHS) Health Resources and Services Administration. Dr. Weiss provided an overview of the need for caregiver education and training, along with a description of the Health Resources and Services Administration (HRSA) caregiving programming and the federal resources available for the development of the caregiver workforce.

As Dr. Weiss noted, approximately 53 million caregivers currently provide care in the home. She added that in recent years the number of caregivers has increased due to the rising number of baby boomers requiring more care; workforce shortages in health care, particularly long-term services; improved efforts by states to facilitate home and community-based services; and increased self-identification as a caregiver. She went on to share recommendations on workforce development and on how to better prepare healthcare professionals to provide family and person-centered care. (Please see Image 1 for more information).

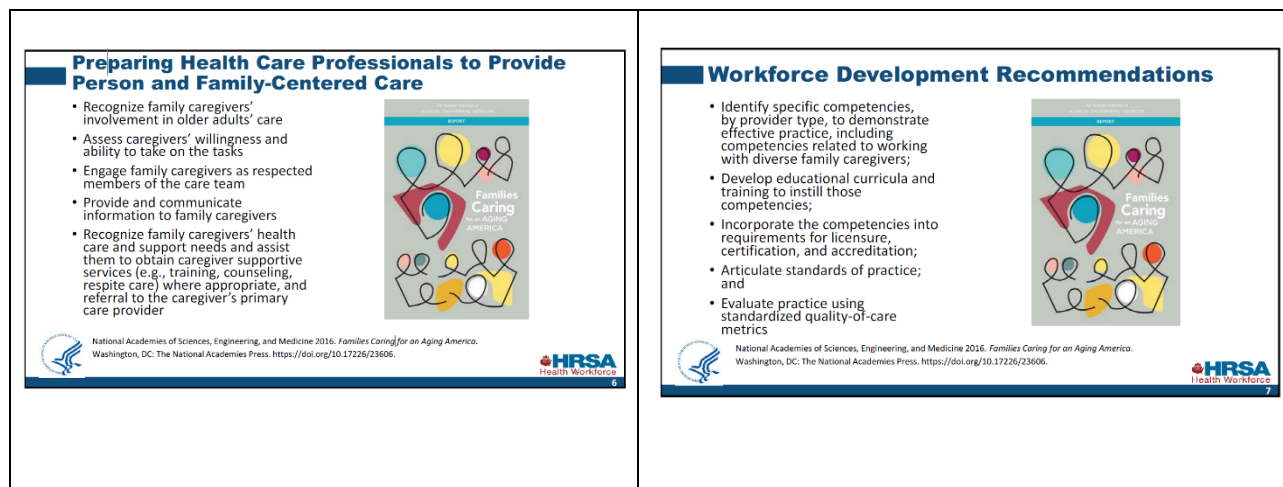


Image 1. Recommendations on Preparing Health Care Professionals to Provide Person and Family-Centered Care

Dr. Weiss also provided an overview of the **Geriatrics Workforce Enhancement Program (GWEP)**, which is focused on developing a healthcare workforce that provides value-based care, improves health outcomes for older adults by maximizing patient and family engagement, and integrates geriatrics and primary care. Forty-eight awards, totaling \$35.9 million, were presented in fiscal year 2020 for this program. Each GWEP must include an evaluation plan that demonstrates the impact of the program on patient access, as well as quality and cost measures. More information on the GWEP program can be found on the websites of HRSA (<https://bhw.hrsa.gov/grants/geriatrics>) and the AGS Geriatric Healthcare Professionals (<https://www.americangeriatrics.org/programs/gwep-coordinating-center>).

Dr. Weiss concluded her talk with a presentation of national resources available to support family caregivers, such as RAISE Family Caregiving Advisory Council, National Family Caregiver Support Program, as well as programs within the Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, and the National Institute on Aging: Alzheimer’s and Related Dementias Care and Caregiving Activities. (Please see Table A for resources presented by Dr. Weiss.)

**Table A: Federal Programs and Resources to Support Family Caregiving**

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| <ul style="list-style-type: none"> <li>• Administration for Community Living National Family Caregiver Support Program: <a href="https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program">https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program</a></li> <li>• Advisory Council to Support Grandparents Raising Grandchildren: <a href="https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0">https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0</a></li> <li>• Centers for Disease Control and Prevention Care Plans Help Older Adults and Caregivers: <a href="https://www.cdc.gov/aging/publications/features/caregiversmonth.html">https://www.cdc.gov/aging/publications/features/caregiversmonth.html</a></li> <li>• Centers for Disease Control and Prevention Caregiving for a Person with Alzheimer’s Disease or a Related Dementia: <a href="https://www.cdc.gov/aging/caregiving/alzheimer.htm">https://www.cdc.gov/aging/caregiving/alzheimer.htm</a></li> <li>• Centers for Disease Control and Prevention Caregiving for Family and Friends – A Public Health Issue: <a href="https://www.cdc.gov/aging/caregiving/caregiver-brief.html">https://www.cdc.gov/aging/caregiving/caregiver-brief.html</a></li> <li>• Centers for Disease Control and Prevention Caregiving: A Public Health Priority: <a href="https://www.cdc.gov/aging/caregiving/index.htm">https://www.cdc.gov/aging/caregiving/index.htm</a></li> <li>• Centers for Disease Control and Prevention Caring for Yourself When Caring for Another: <a href="https://www.cdc.gov/aging/publications/features/caring-foryourself.html">https://www.cdc.gov/aging/publications/features/caring-foryourself.html</a></li> <li>• Centers for Disease Control and Prevention: <a href="https://www.cdc.gov/aging/index.html">https://www.cdc.gov/aging/index.html</a></li> <li>• Geriatrics Academic Career Award (GACA) Program: <a href="https://www.hrsa.gov/grants/find-funding/hrsa-19-007">https://www.hrsa.gov/grants/find-funding/hrsa-19-007</a></li> <li>• Improving Care for People with Alzheimer’s Disease and Related Dementias Using Technology (iCare-AD/ADRD) Prize Challenge: <a href="https://www.nia.nih.gov/icare-ad-adrd-eureka-challenge-winners">https://www.nia.nih.gov/icare-ad-adrd-eureka-challenge-winners</a></li> <li>• National Institute on Aging: Alzheimer’s and Related Dementias Care and Caregiving Activities: National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: 2017 &amp; 2020 (virtual): <a href="https://www.nia.nih.gov/2020-">https://www.nia.nih.gov/2020-</a></li> </ul> |
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[dementia-care-summit](#)

- NIA IMbedded Pragmatic Alzheimer's disease and Alzheimer's-related Dementias Clinical Trials (IMPACT) Collaboratory: <https://impactcollaboratory.org/overview/>
- RAISE Family Caregiving Advisory Council: <https://acl.gov/programs/support-caregivers/raise-family-caregiving-advisory-council>
- Care interventions for People Living with Dementia and Their Caregivers: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report>

*Links active as of November 19, 2020*

## Panel 1: Workforce Education for Family Caregiving

**Facilitator:** Janice Bell, Ph.D., M.P.H., M.N., F.A.A.N.

Betty Irene Moore School of Nursing at UC Davis

### **Working with Family Caregivers: Engaging Health Professional Students from Undergraduate Through Doctoral Levels at USF**

William Haley, Ph.D.; Kathryn Hyer, Ph.D., M.P.P.; Brianne Stanback, Ph.D.  
University of South Florida

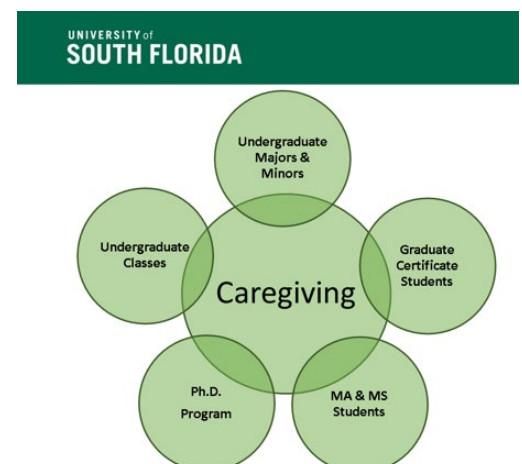
### **Building Caregiver Partnerships through Innovative Health Professions Education**

Margaret Sanders, M.A., L.S.W.; Barbara Palmisano, M.A., R.N.; Jennifer Drost, D.O., M.P.H.  
Northeast Ohio Medical University

### **Development and Implementation of a Graduate Certificate and Continuing Education Program in Family Caregiving**

Kathryn Sexson, Ph.D., A.P.R.N., F.N.P.-B.C.; Lisa Badovinac, M.A.  
Betty Irene Moore School of Nursing at UC Davis

The first panel highlighted education, from undergraduate programs to continuing education. **Dr. William Haley** from the University of South Florida (USF) provided an overview of the diverse ways the topic of caregiving is integrated into educational programs, both through incorporation into existing School of Aging courses as well as stand-alone caregiving courses that provide in-depth training on the subject. USF integrates caregiving into courses at the



*Image 2: University of South Florida Caregiving Education*

undergraduate, graduate, and doctoral levels (Figure 1), with the goal of having all students exposed to the topic of caregiving during their training, and the hope that some students will pursue specialization. This is accomplished through coursework, internships, engagement with alumni and community partners, and participation in research.

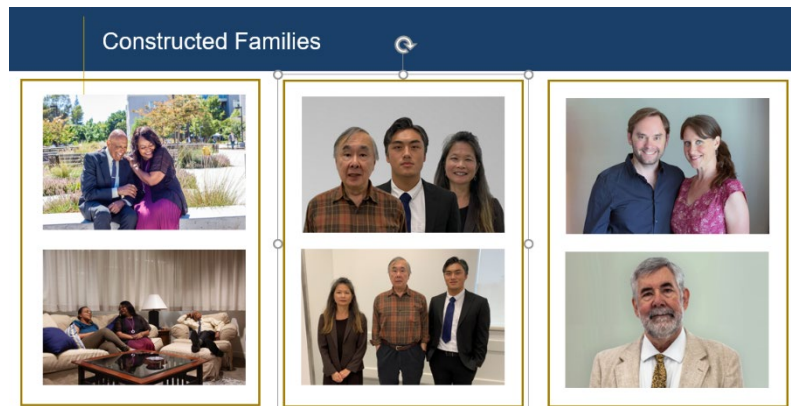
**Dr. Margaret Sanders** from the Northeast Ohio Medical Center provided an overview of training programs, coursework, and experiential exercises for healthcare providers and students at multiple clinical and academic sites. The material—designed to enhance the caregiving experience for the patient, family, and providers—helps guide and generate discussions of elder care. In addition, a compendium of web-based curricula includes discussion guides, case-based learning exercises, structured clinical encounters and team simulations. Dr. Sanders’s team also developed undergraduate and graduate medical education packages.

To date, 169 internal and family medicine residents from seven residency programs in four communities have received the graduate medical education training, and 1,557 medical and pharmacy students have received the undergraduate curricula. Additionally, 56 faculty members representing nine disciplines, and 407 healthcare providers representing seven disciplines, have received the training. Some of the students and providers participated in more than one of these offerings. (See Image 3 for more information.)

<h3>Graduate Medical Education Package</h3> <ul style="list-style-type: none"><li>• Developed 8 clinical cases with objectives and discussion questions for case-based learning</li><li>• Mapped cases to ACGME milestones for FM and IM</li><li>• Developed a learner assessment tool based on ACGME milestones to measure impact of caregiver training on residents</li><li>• Trained 169 FM and IM residents from seven residencies in four communities</li><li>• 97% of trained residents reported increased awareness of issues faced by caregivers and 99% had increased awareness of caregiver needs</li></ul>	<h3>Undergraduate Interprofessional Education Package</h3> <ul style="list-style-type: none"><li>• Funded by HRSA GWEP</li><li>• Website offerings include educational modules for medicine, pharmacy and nursing students with suggestions for discussions and clinical experiences</li><li>• IPE format for team simulations available with examples of team-based activities (e.g. team building, huddles, debrief, etc.)</li><li>• Trained 2596 health professions students in 13 disciplines from 7 Ohio universities</li></ul>
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*Image 3: Building Caregiver Partnerships through Innovative Health Professions Education*

**Dr. Kathryn Sexson and Lisa Badovinac** from the Family Caregiving Institute at the Betty Irene Moore School of Nursing at UC Davis presented a description of the development and results of a pilot project of a graduate academic certificate program in family caregiving implemented in 2019-2020. Composed of three



*Image 4: Constructed Families for Graduate Academic Certificate in Family Caregiving*

with both graduate nursing students and community nursing partners, the project’s purpose was to promote clinical care that ensures comprehensive assessment of both patients and family caregivers and encourages the integration of family caregivers in the healthcare team; supports family caregivers in fulfilling their role across the trajectory of illness; and introduces a paradigm shift from patient-centered care of the adult to family-centered care that includes the caregiver.

The first course is theoretical and focuses on various assessment measures. The second course, which incorporates case-based learning, introduces three families (Image 4) whose stories unfold through a series of online simulations, synchronous debriefings, and reflections. The third course further explores the family cases and focuses on the construction of a co-created care plan. The graduate academic certificate is being adapted into a series of modules for continuing professional education in all health professions.

## Poster Sessions

The day ended with a 45-minute facilitated poster session that featured twelve presenters in four Zoom rooms. Presenters had twelve minutes to review their posters, with additional time allotted for questions and answers. Participants could ask questions through the chat function or by raising their virtual hand. A UC Davis school of nursing faculty member facilitated each Zoom room to assist with the session and to monitor questions. Similar to an in-person poster session, individuals could go in and out of the four Zoom breakout rooms to learn about different posters and chat with presenters.

<p><b>The Caregiver Health and Wellness Initiative in the Healthcare System: An Evidence-Based Model for Systemic Change and Improved Outcomes</b></p> <p>Alexandria Vernasco, M.S.W.; Ellen Carbonell, M.S.W.; Vikki Rompala, M.S.W., Ph.D. Social Work and Community Health Rush University Medical Center</p>
<p><b>Where are the Family Caregivers? Creating Guidance for the Nursing Profession</b></p> <p>Sara Hart, Ph.D., M.S., B.S.N.; Lee Ellington, Ph.D., Kristin Cloyes, Ph.D., M.N., R.N.; Ann Kuglin Jones, M.S.N., M.B.A., R.N., A.O.C.N., F.A.C.H.E University of Utah College of Nursing</p>
<p><b>Geriatrics and Gerontology MOOC to Improve Intention to Work with Older Adults and their Families</b></p> <p>Anna Zisberg, R.N., Ph.D.; Orly Tonkikh, R.N., M.A.; Ksenya Shulyaev, Ph.D., R.Psy. The Cheryl Spencer Department of Nursing University of Haifa</p>
<p><b>Assessing the Efficacy Of Didactic Modules in Training Health Care Professionals in Interprofessional Geriatrics Care</b></p> <p>Rida Altaf, OMS-2; Sravya Emmadi, B.S.; Sweta Tewary, Ph.D., M.S.W., M.S.MIS; Naushira Pandya, M.D., C.M.D., F.A.C.P; Nicole Cook, Ph.D., M.P.A. Kiran C. Patel College of Osteopathic Medicine Nova Southeastern University</p>
<p><b>Nursing Student Led Online COVID-19 Education for In-Home Supportive Service Caregivers</b></p> <p>Jung-Ah Lee, Ph.D., Julie Rousseau, Ph.D., A.P.R.N., C.N.M; Neika Saville, M.Ed.; Sara Brown, Ed.D., R.N.; Huy Nguyen, B.S.; Lisa Gibbs, M.D., School of Nursing University of California, Irvine</p>
<p><b>Pilot Analysis of ADRD Education and Training on General Dementia Knowledge among Primary Care Professionals</b></p> <p>Scott Wilks, Ph.D., M.S.W.; Sarah Choate, M.S.W.; Katherine Kirsch, M.S.W.; Laura Ainsworth, Ph.D., L.C.S.W.; Catherine Lemieux, Ph.D., L.C.S.W.-B.A.C.S. School of Social Work Louisiana State University</p>
<p><b>Educational Resources for Nursing Home Providers: Engaging Family Members in this COVID Era</b></p> <p>Jennifer Birdsall, Ph.D. CHE Behavioral Health Services</p>
<p><b>Dementia 360: Clinician Education and Support Beyond City Limits</b></p> <p>Allison Lindauer, Ph.D., A.P.R.N.; Katherine Wild, Ph.D., Deborah Messecar, Ph.D., P.M.H., R.N., A.G.C.N.C.-B.C., C.N.E.; Andrew Natanson, M.D., M.S.; Nora Mattek, M.A.; Miriam Wolf; Anna Steeves-Reece, M.P.H., M.A. Layton Aging and Alzheimer's Disease Center; Oregon Health &amp; Science University</p>
<p><b>Improving Mental Health for Veterans With Dementia: Provider Training in Family Caregiver Engagement</b></p> <p>Mary Wyman, Ph.D.<sup>▲</sup>; Corrine Voils, Ph.D.<sup>‡</sup>; Ranak Trivedi, Ph.D.<sup>▲</sup>; Carey Gleason, Ph.D.<sup>‡</sup>; Amy Byers, Ph.D.<sup>*</sup> <sup>▲</sup>University of Wisconsin/Veterans Affairs; <sup>‡</sup>University of Wisconsin/WS Middleton Memorial Veterans Hospital; <sup>▲</sup>Stanford University/Palo Alto VA Medical Center; <sup>*</sup>University of California, San Francisco/San Francisco VA Medical Center</p>
<p><b>Training Healthcare Professionals to Deliver Virtual Group Caregiving Support Classes in a VA Setting</b></p> <p>James Powers, M.D.; Jacy Weems, B.S.</p>



Medicine/Geriatrics

Vanderbilt Center for Clinical Quality and Implementation Research

**Delivering and Embedding Dementia-Friendly Training in a Health Care System**

Ellen Schneider, M.B.A.; Maureen Dale, M.D.; Krista Wells, M.S.N., R.N., C.C.R.N.; John Gotelli, MSN, Julian, B.A.; Cristine Henage, Ed.D.; Jan Busby-Whitehead, M.D.; Ellen Roberts, Ph.D.

UNC-Chapel Hill

**Social Work Interventions for Transforming Dementia Care (SWIFT-DC)**

Steven Tam, M.D. <sup>▲</sup>; Victoria Lowerson Bredow, M.P.H., Ph.D. <sup>▲</sup>; Bryan Robles<sup>▲</sup>; Mark Odom L.C.S.W.<sup>#</sup>; Lynne Conger L.C.S.W.<sup>#</sup>; Nikki Barrett L.C.S.W.<sup>#</sup>; Lisa Gibbs, M.D. <sup>▲</sup>

<sup>▲</sup>Family Medicine, University of California, Irvine; <sup>#</sup>Alzheimer's Orange County

## Panel 2: Workforce Education for Family Caregiving

**Facilitator:** Elena Siegel, Ph.D., R.N.

Betty Irene Moore School of Nursing at UC Davis

### **Caring for Those Who Care: Meeting the Needs of Diverse Family Caregivers – Training Curriculum**

Lauren Pongan, M.A.

Diverse Elders Coalition

### **Certificate on Carer-centered Care Management for Professional Practitioners**

Vivian Lou, Ph.D.

The University of Hong Kong

### **Introduction to Family Caregiving Across the Lifespan: Promoting intergenerational and multidisciplinary student course learning**

Jamie Penner, R.N., Ph.D.(c); Michelle Lobchuk, R.N., Ph.D.

University of Manitoba

**Laura Pongan** from the Diverse Elders Coalition (DEC) began the second panel with an overview of the unique experiences and challenges faced by diverse elders and carers. In her presentation ***Caring for Those Who Care: Meeting the Needs of Diverse Family Caregivers***, Pongan reported that 20% of elders in the country are a person of color and 37% are lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ).

DEC and the Benjamin Rose Institute on Aging collaborated on the diverse family caregiving survey to identify the stressors of caregiving, well-being outcomes, and support resources for caregivers and care receivers.

Focus groups were held with caregivers in eight languages and in 15 cities across the country.

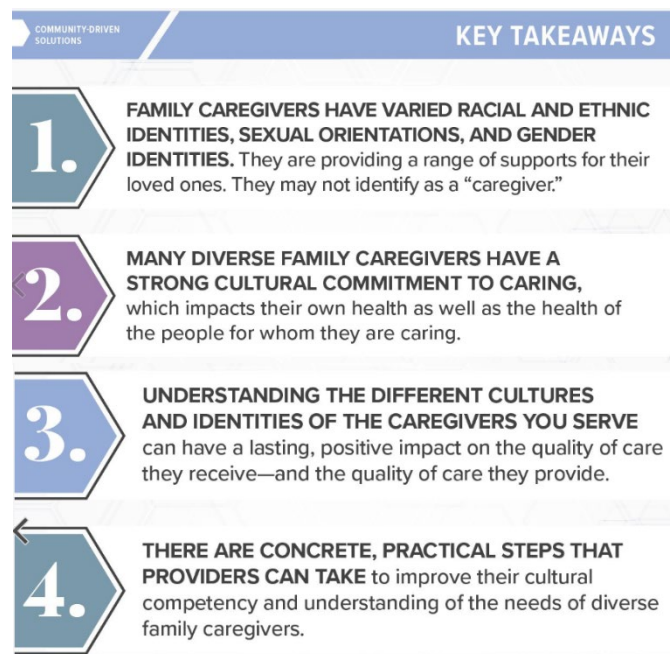


Image 5: Takeaways from the Diverse Family Caregiving Study.

The surveys and focus groups identified common challenges across groups, as well as the impact of culture on an individual's sense of obligation to serve as a caregiver. (Image 5 includes key lessons learned from the study.)

**Dr. Vivian Lou** from the University of Hong Kong described an educational program developed through the Sau Po Centre on Aging, consisting of a four-hour foundations course and a 48-hour certificate course. The foundations course focuses on building capacity for 1) risk

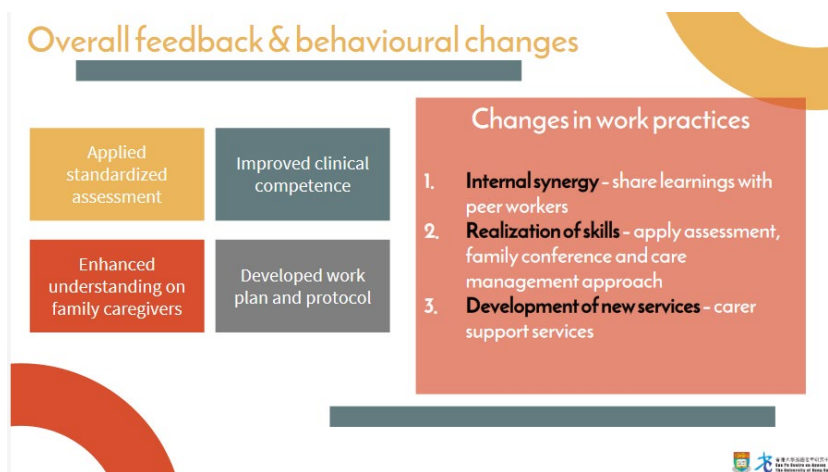


Image 6: Evaluation of Certificate on Carer-Centered Care

screening to identify needs; 2) multi-dimensional carer assessment interventions; and 3) care management framework centered on the caregiver. The certificate course includes a review of care management and caregiver burden; depression and mental illness; family perspective, and family

mediation. Over 500 people participated in the foundations course and 75 completed the certificate course. Evaluations indicated a high-level of satisfaction with the course material and changes in the participants' understanding and behavior (see Image 6).

**Doctoral candidate Jamie Penner and Dr. Michelle Lobchuk** from the University of Manitoba completed the second panel with a presentation on a blended delivery course titled,

**Introduction to Family Caregiving Across the Lifespan: Promoting intergenerational and multidisciplinary student course learning**, which introduces the concept of family caregiving to multidisciplinary undergraduate students through an interdisciplinary and intergenerational approach. In this course students engage with information regarding caregivers and the vital role(s) they play in supporting those who have physical, psychological, or developmental needs. They also

### HOW TO DESIGN & IMPLEMENT: TIP #1

Ensure course content is evidence-informed and guided by multidisciplinary lens

### HOW TO DESIGN & IMPLEMENT: TIP #2

Provide in-class opportunities to engage in intergenerational dialogue

### HOW TO DESIGN & IMPLEMENT: TIP #3

Develop a series of "It Takes a Village" assignments

### HOW TO DESIGN & IMPLEMENT: TIP #4

Engage in community outreach to stimulate community interest in course

explore ethical, legal, economic, and policy issues related to caregiving, as well as topics concerning wellness and health-related quality of life. Dialogue and joint learning between multidisciplinary undergraduate students and intergenerational learners are key aspects of this course.

The presenters offered four lessons on design and implementation:

- 1) Ensure that course content is evidence-informed and guided by a multidisciplinary lens in order to better understand and “realistically” support caregivers.
- 2) Provide learners with in-class opportunities to engage in intergenerational dialogue that bolsters sensitive understanding of caregiver issues. Therefore, make course registration open to community members, including older adults.
- 3) Develop a series of “It Takes a Village” assignments that help learners identify their unique disciplinary understanding of caregiver issues; increase confidence in students’ ability to advocate for caregiver-centered care; and allow multidisciplinary and intergenerational learners to devise an interdisciplinary intervention plan to address a caregiver issue.
- 4) Encourage instructors to engage in community outreach in order to stimulate interest in the course.

## World Café Sessions

A series of small group discussions were held based on the World Café™ method of facilitating dialogue among large groups. Participants were randomly assigned to a cohort and each cohort rotated through three 20-minute discussions on the following topics: Working Effectively with Diverse Caregivers; Incorporating the Family Caregiver into the Healthcare Team; and Supporting Family Caregivers During the COVID-19 Pandemic. To keep the groups under 15 people and encourage participation, each topic had two separate discussion groups led by faculty members of the Betty Irene Moore School of Nursing at UC Davis

### Working Effectively with Diverse Caregivers:

- Education: Provide education and training for the entire care team (including the patient, clinicians, and the caregiver), focusing on cultural humility and relinquishing stereotypes.
- Communication: Encourage one-on-one conversations with caregivers and acknowledge both the similarities and differences across diverse communities and cultures. In

addition, bear in mind that within any culture, family members from different age groups may hold various opinions on caregiving.

- **Assessment:** Conduct comprehensive assessments that include the values and preferences of the patient and the caregiver. Furthermore, consider the caregiver's literacy level; use language that's clear and understandable and help them identify additional resources and support.
- **Institutional Racism:** Acknowledge that individuals' previous negative experiences with healthcare—caused by institutional racism—may result in mistrust of the system. Deliver person-centered care that is focused on building trust. Allow the patient and their family to drive the conversation.
- **Community Partnerships:** Clinicians can leverage community organizations, learners from different professions, and peer groups to encourage learning from one another and reduce the power differential.

### Incorporating the family caregiver into the Healthcare Team

- **Education and training:** Create educational programs for both healthcare students and practicing clinicians on how to best support family caregivers. Encourage dual certification on geriatrics to other providers, and include questions on family caregiving in certification exams, including NCLEX. Providers need to have an understanding of the importance of family caregivers in order to fully grasp the potential for their role, prepare them to be part of the interprofessional team, and anticipate what questions to ask.
- **Healthcare infrastructure and systems:** Institutionalizing the role of caregivers will keep the caregiver from becoming vulnerable to the individual discretion of providers. Consistent messaging should be threaded through the entire system, starting with the front desk and continuing through all healthcare personnel who interact with patients and their families. Address the reluctance of providers who believe that integrating the caregiver into the care team is too time-consuming.
- **Communications:** Family caregivers should be incorporated into the discussion at the start of care, and all team members should have a clear understanding of their roles and expectations. Acknowledge care team or networks of caregivers, making them visible through care mapping or network mapping.
- **Policy:** Advocate for reimbursement for the time spent providing support to family caregivers (e.g., education, resource referral, case management) by informing policy makers of the cost-saving potential of family caregivers.



- Research: Conduct research that not only helps identify caregivers, but also includes data that can be used to advocate for resources and system changes to support caregivers.
- Outreach: Conduct lunch and learns, blogs, and other activities to reach healthcare professionals and caregivers on the key topics discussed at this meeting.

## Supporting Family Caregivers During the COVID-19 Pandemic

- Stress and Isolation: Caregivers have long reported stress and isolation as part of their role. These have worsened during COVID-19, with many caregivers simultaneously caring for children learning from home and for an older family member. Some caregivers are providing care at a distance, which may cause additional stress. Finally, caregivers may be experiencing an increasing sense of grief and loss. Healthcare professionals must be able to assess and recognize these issues and provide support and resources.
- Technology: Reliance on technology has vastly risen during the pandemic, not only for accessing healthcare and other services, but also for connecting with others. It's important to recognize that Individuals have different skill levels and comfort in the use of technology, as well as varying reliability of internet service.
- Self-Care: Frequently, caregivers ignore their own physical well-being and mental health. Providers and others should share websites and other resources (for example, YouTube videos on meditation, exercise, and stress relief), as well as information on how to navigate these sites. They can also encourage alternate modes of communicating with family and friends (such as the telephone).
- Health Systems: Health systems should re-examine visitation policies to ensure that caregivers can continue to be part of the team and assist in the care of family members receiving hospital care. Clinical education programs need to focus on these areas and acknowledge the important role of the caregiver.
- Opportunities: Despite the difficulties it has brought on, the pandemic also presents us with opportunities. For example, such policy changes as reimbursement for telehealth have increased access to healthcare. There is opportunity in crisis: discussions on affordability and connectivity—triggered by the pandemic—offer us a chance to look for innovative solutions to economic inequities.

## Reaction Panel

The final panel of the summit included reactions to the discussions by representatives from government, professional, community, and private funding organizations. Each panel member was asked to consider the following questions in their response:

1. Please describe how the information shared at the summit fits within your organization's priorities and the people you serve?
2. Are there issues or points of view that were not represented at the summit that are important for us to consider?

### **Rita B. Choula, M.A.**

Director, Caregiving

*AARP Public Policy Institute*

Rita Choula reflected on the summit discussions and stressed the enormity of the role of family caregivers. According to research conducted by AARP and the National Alliance for Caregiving, there are 53 million adult children, grandchildren, parents, spouses, partners, neighbors and friends who are providing care to people aged 18 and older. This care—entirely unpaid—is valued at approximately \$475 billion a year. In 2020, caregivers' stress only increased, from such factors as the COVID-19 pandemic, wildfires, and the heightened awareness of social and racial inequalities. Feedback from an AARP project with caregivers showed that family caregivers are buckling under the weight of isolation, fear, an uncertain future, and the absence of a clear path. Choula noted that to support caregivers, AARP created partnerships with other organizations present at the summit, focusing on such areas as advocacy, research, professional education, and consumer support. It also created educational videos on a variety of caregiving topics, including medication management, incontinence, and special diets.

The summit, Choula added, helped to identify strategies to address gaps in education and curriculum development. Providers need to better support family caregivers, understand the importance of including them in the care team, and recognize the challenges they face and the stress they experience. Existing curricula, such as the National League for Nursing's ACE.C (Advance Care Excellence for Caregivers) program—a simulation program that helps nurses communicate better with family caregivers—can be a good starting point. (see: <https://www.nln.org/education/teaching-resources/professional-development-programsteaching-resourcesace-all/ace-c>).

In order to create an inclusive an inter-professional team, the system must change. Otherwise, Choula warned, gaps in service and access will continue to widen, and caregivers' needs will fall through the cracks.

Choula concluded on the topic of diverse family caregivers. Society, she said, is growing increasingly diverse, but much of the caregiving research that that has been conducted thus far has primarily focused on white female caregivers. Programs and systems changes designed to reflect the results of those studies may not be effective in addressing the needs of family caregivers from varying cultures, races, and backgrounds.

**Patricia M. D'Antonio, BS.Pharm., M.S., M.B.A., B.C.G.P.**

Vice President, Professional Affairs

*The Gerontological Society of America*

The Gerontological Society of America (GSA) takes a 360-degree perspective on aging, which is why family caregiving is such an important issue for the association and its members. The topic of family caregiving is in the top five abstract submissions for the organization's annual scientific meeting and is frequently published in GSA journals. GSA also includes a robust and active family caregiving interest group, which communicates through GSA Connect, an online platform that connects people from various professions and geographic locations and provides GSA with feedback that informs education and policy.

D'Antonio, noting the importance of being mindful of implicit bias regarding aging while developing programs, shared various resources, including The Reframing Aging Initiative, which reframes the way people think about aging (<https://www.reframingaging.org>), and the KAER Model Cognitive Impairment Toolkit, which includes approaches and tools for early identification of cognitive impairment (<https://www.geron.org/programs-services/brain-health-cognitive-impairment-and-dementia?start=1>).

**Nina Tumosa, Ph.D.**

Public Health Analyst

Division of Medicine and Dentistry

Bureau of Health Workforce

*DHHS Health Resources and Services Administration*

Dr. Nina Tumosa provided feedback from the point of view of the federal government. The summit presentations and discussions, she said, reiterated the notion that caregiving is a "team sport," and the patient and family must be integral to the care team. She added that while

many might agree with this notion, not all providers demonstrate it in practice. The discussions illustrated a variety of opinions on what it means to have a patient and family central to the team and provided multiple examples of how to promote that concept through education and training. Tumosa noted the need to do more.

During the summit many recommendations were shared on how to provide training to healthcare professionals, identify training partners, and promote safety and justice for patients and families while protecting their autonomy. Participants also stressed the importance of including family caregivers when designing programs and resources, and incorporating issues related to family caregiving on certification tests.

Tumosa stressed the federal government's commitment to training and education in this area, adding that many of the programs highlighted during the summit were developed through federal grants and contracts. She also emphasized the importance of sharing resources, as well as recommendations, barriers, challenges, innovations, and potential solutions through meetings, abstracts, posters, and publications.

**Nancy R. Zweibel, Ph.D., F.G.S.A.**

*Senior Program Officer*

*RRF Foundation for Aging (RRF)*

Dr. Nancy Zweibel provided the perspective of a private foundation. Last year, she said, RRF transitioned from a responsive grant foundation to an organization that focuses on four priorities for grants, including caregiving. Zweibel noted that given the breadth of discussions at the summit, more work is required on multiple levels. She emphasized the role of advocacy, including the need for payment reform and for health systems to recognize the cost benefit of effective programs—particularly care transitions—involving older adults and their caregivers. Also important are curriculum standards for health care providers and others, including social workers. Zweibel highlighted such initiatives as the RAISE Act Advisory Council, which funds community-based organizations catering to older adults and people with disabilities, and invests in research, education, and innovation. Zweibel also stressed the need for further research on training programs, cost effectiveness for health systems, and payment reform.

## Closing Remarks

The summit closed at 1p.m. on September 17<sup>th</sup> with brief remarks by Dr. Terri Harvath.