The 2021 Conference on Engaging and Supporting Care Partners of Persons with Dementia in Healthcare Delivery:

Key Findings and Recommendations

1. **IDENTIFICATION AND ASSESSMENT:** *Establish best practices for effectively and sensitively identifying and assessing ADRD care partners in healthcare settings.*
   1. Conduct stakeholder engaged research with caregivers from diverse backgrounds to design identification and assessment protocols that are responsive to the heterogeneity in patients’ and care partners’ circumstances (e.g., presence of multiple caregivers) and preferences (e.g., how care partners wish to be referenced during a medical visit).
   2. Develop standardized tools that can be integrated within health information technologies (e.g., the electronic health record) and promote accurate identification of care partners in medical settings, both through their own interactions with the health care system and by their attendance at their care recipient’s medical appointments.
   3. Attend to racial, cultural, class, and ethnic differences in caregiver identification and assessment, including the impact of implicit and explicit biases by providers as well as the stigma of seeking help for being a “caregiver.”
   4. Evaluate whether and how identifying and supporting care partners earlier in their care recipient’s disease trajectory may impact care quality and health-related outcomes for persons with ADRD and their care partners.
   5. Collaborate with healthcare systems and payment plans (Medicare and Medicaid) to embed and reimburse for care partner identification and assessment procedures in routine care delivery.
2. **TRAINING AND SUPPORT ACROSS THE CARE CONTINUUM:** *Design evidence-based practices and training programs to support ADRD care partners across the continuum of care.*
   1. Identify and subsequently implement and disseminate best practices for facilitating ADRD care partner referrals from medical settings to community-based services and to ongoing clinical trials; compare these practices across healthcare settings and systems of care.
   2. Develop unified models of care delivery that support ADRD care partners across the care continuum and especially during critical care transitions (e.g., into assisted living or nursing home settings).
   3. Leverage intersectionality frameworks to consider how multiple factors (e.g., culture, race, gender, socioeconomic status) may affect ADRD care partners’ interactions within and across healthcare systems.
   4. Adapt and tailor existing evidence-based interventions to support diverse, marginalized populations (e.g., rural caregivers, caregivers of Veterans, long-distance caregivers) across the care continuum.
   5. Design interventions that extend across each stage in the disease trajectory and are responsive to the changes in care partners’ needs over time.
   6. Develop and test training programs that attend to issues beyond the tasks care partners provide to their care recipient, including help with health literacy and numeracy, financial planning, and end of life planning.
3. **PROVIDER TRAINING:** *Develop education and training programs to support healthcare providers in providing effective and compassionate person- and family-centered dementia care.* 
   1. Design and implement evidence-based curricula that prepares medical professionals – defined broadly to include nursing home and home health care aides, case managers, service coordinators, and community health workers – to deliver culturally competent, person- and family-centered care that addresses implicit and explicit biases about caregivers’ abilities, backgrounds, and motivation.
   2. Develop training programs to help healthcare providers navigate “shared care” encounters in which a person with ADRD has a network of multiple care partners.
   3. Develop and test the impact of provider communication skills training on patient and care partner outcomes, including care quality and satisfaction.
4. **IMPLEMENTATION, DISSEMINATION, AND SUSTAINABILITY:** *Achieve consensus on best practices for supporting future implementation, dissemination, and sustainability of ADRD care partner interventions in community and healthcare contexts.*
   1. Develop a systematic, unified strategy – guided by the existing evidence – for advancing the science of implementation and dissemination research on ADRD caregiving.
5. Leverage and combine models of inclusion, equity, and intersectionality with community-driven approaches to engage stakeholders from diverse minority groups in every aspect of the study design, from the study’s inception and to dissemination.
   1. Establish best practices for expanding the scale and reach of evidence-based interventions for ADRD care partners that take into account unique contextual considerations.
   2. Develop and test promising strategies for monitoring intervention fidelity and promoting sustainability after implementation in community and clinical settings.
   3. Conduct a portfolio analysis of funding mechanisms focused on implementation, dissemination, and sustainability to stimulate greater emphasis on this type of funding and raise awareness among researchers regarding potential opportunities in this area.
   4. To foster implementation of evidence-based interventions, develop and test caregiver programs that are ancillary to direct care services but integrated patient systems of care.
6. **REIMBURSEMENT AND FINANCING:** *Conduct cost-effectiveness studies that move beyond traditional economic indicators to evaluate macro-level outcomes and unintended consequences of payment reforms.*
   1. Determine the prevalence of and barriers to the use of payment mechanisms that enable healthcare providers to bill for services provided to an ADRD care partner who is not his or her patient (e.g., chronic care management and transitional care codes).
   2. Identify what incentives may promote healthcare systems’ uptake and use of care partner-focused reimbursement codes.
   3. Evaluate the longitudinal benefits of ADRD care partner interventions on macro-level outcomes, including effects on labor supply, work productivity, and tax revenues.
   4. Design studies that measure the potential unintended consequences of new and existing public policies and payment reforms on ADRD caregivers, and use the findings to promote policy changes (e.g. paid family leave).

**VI. TECHNOLOGY:** *Examine technology that can facilitate remote delivery of ADRD caregiver assessment and interventions and provide support for persons with ADRD and their care partners.*

1. Determine how the electronic health record (EHR) and other interoperable devices may assist with identifying ADRD care partner(s) and assessing their respective contributions and needs.
2. Leverage technology to facilitate the remote delivery of evidence-based interventions and evaluate how unequal access (e.g., to smart phones, internet) may limit broader reach.
3. Evaluate whether and how existing technologies (e.g., EHR) may lead to gaps in care for minority groups where current identification strategies may not be culturally congruent
4. Build on existing digital infrastructures (patient portals, electronic care plans, apps) to support ADRD care partners and share information across providers and care settings.
5. Identify and evaluate technology applications that can provide support for the caregiving role (e.g., monitoring, assisting with ADL/IADL support for the care recipient) and how to best integrate these applications with care plans.