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RE: Notice Number: NOT-AG-19-016, Invitation for Input on the 2020 National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers

Dr. Fazio and Dr. Wallin:

Thank you for the opportunity to offer input into the agenda for the next Dementia Care and Caregiving Summit, to be held in 2020. We represent the ARCH National Respite Network and Resource Center, which is funded by the Administration for Community Living to house the Lifespan Respite Technical Assistance Center. Respite care to improve caregiver health and well-being is a central focus of the Resource Center’s activities.

We note that the primary goals listed in the Invitation for Input (Notice Number: NOT-AG-19-016) relate primarily to the provision of care to the person living with dementia by sharing research findings, participating in research on care for persons living with dementia, improving intervention research to improve the care available to persons living with dementia, and supporting their caregivers.

ARCH representatives attended the first National Respite Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers in 2017. In the area of caregiver supports, the Summit focused on training caregivers to be more effective caregivers, increasing caregiver skills, and developing technology to assist caregivers in their role. Skills training and caregiver education are critically important strategies to safeguard the health and well-being of caregivers. However, there was little mention of the important role that respite care can play in alleviating caregiver stress and burden, which is directly linked to caregiver health and well-being. Respite can also play an important role in helping to link family caregivers to additional supports, including caregiver skill-building and training opportunities. Since 2014, ARCH has been engaged in a process to improve the evidence base for respite care as a service to caregivers of persons living with dementia as well as caregivers for adults...
and children living with a variety of other disabling diseases and conditions. ARCH convened an Expert Panel on Respite Research to assist in this endeavor, and began the process with a comprehensive review of respite research from the preceding two decades, resulting in publication of an annotated bibliography on respite care.

Providing daily care is typically a ceaseless and sometimes complex task, and many caregivers are, themselves, older adults with their own health issues. While many caregivers derive emotional rewards from their caregiving experience, many caregivers experience physical and emotional problems directly related to the stress and demands of daily caregiving. Family caregivers typically experience a decline in their own physical and emotional health as a direct result of caregiving. The impact of the role of caregiving and its detrimental impact on caregiver health and well-being increases risk for hospitalization and institutionalization of the person living with dementia or other disabilities.

Respite services are among the most frequently requested services from caregivers, but 85% of caregivers of adults are not receiving respite. Respite use is especially underutilized and/or delayed among caregivers of persons with dementia. Caregiver feelings of loss of control, sadness, guilt, and a sense of failure if respite care is needed has been documented among family caregivers of individuals with dementia.

Among the most salient findings from that review that are of potential interest for planning the 2020 Dementia Care and Caregiving Summit, are:

- Much of the research on respite over the last two decades has focused on individuals with dementia, including Alzheimer’s disease. The respite model most frequently studied was adult day services. There is a need to study other respite models, including professional in-home care, volunteer and companion care in-home or community settings, community outings and engagement for people with dementia, and other innovative respite approaches.
- Work by Dr. Dale Lund and colleagues have found that what caregivers do with their respite time is as significant, if not more significant than the type of respite care provided to the care recipient, in maintaining longer-term beneficial effects for the caregiver. This aspect needs to be studied further.
- While Dr. Steve Zarit and his colleagues have found significant reductions in caregiver stress as a result of adult day service use for people with dementia, most other respite research has focused on care recipient outcomes (e.g., sleep patterns, disruptive behaviors), rather than caregiver outcomes.
- Respite is also most frequently studied as part of multi-component caregiver support program and it is difficult to discern specifically what role respite played or which model or aspect of respite was most beneficial.
Other research findings from respite research have demonstrated high caregiver satisfaction with respite; some evidence of decreased stress, depression and caregiver burden; a relationship between dosage and expectation of respite to stress reduction for caregivers; a suggested relationship between stress reduction and improved health outcomes; and mixed results on delaying out-of-home placement. However, many of these studies had small sample sizes or other methodological flaws.

ARCH defines respite as “planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system.” The Expert Panel in its final report, A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders, made a series of specific overarching recommendations to improve prospective research on respite care including the need to:

- address foundational methodological concerns to strengthen the significance of caregiver outcomes;
- focus research on individual, family, and societal outcomes relating to the health and well-being of both the caregiver and the care receiver;
- carry out appropriate cost-benefit and cost-effectiveness studies of respite care;
- investigate systems changes that improve access to respite;
- evaluate strategies/training/core competencies to improve respite provider quality; and
- conduct translational research that informs respite policy and practice.

The Expert Panel identified improved research methods and topics that would enhance the meaningfulness of the outcomes, including 1) ensuring that the family caregiver is the portal of entry and an important focus of any research study; 2) comparison of different types of respite, not just respite vs non-respite use; 3) investigation of the effects of dosage, timing, and service delivery modes on outcomes; 4) qualitative methods to capture contextual information; 5) a focus on respite only or in combination with other support services; 6) examination of the relative impact of informal family and community support as compared to formal and/or paid respite services; 7) more rigorous consideration and examination of the role of contextual variables, such as demographic variables or racial and cultural differences; 8) development of new instruments or measures with validation of new proximal outcomes specific to respite to increase sensitivity; 9) additional research focused on specific target groups; and 8) longitudinal studies.

ARCH is engaged in a multiyear project to implement these recommendations that will culminate in a Respite Research Summit to be held in June 2020 with support from the Administration for Community Living and in collaboration with the University of Wisconsin-Madison School of Nursing.

With respect to the upcoming 2020 Dementia Care and Caregiving Summit, we respectfully suggest that conference planners include reference to the need for more research on the
benefits of respite care for family caregivers as a stand-alone service, or a service that can be offered in conjunction with other services (e.g., caregiver skills training and education; caregiver support groups and mental health services; social engagement and therapeutic and medical services provided by professional caregivers) in a comprehensive plan of care for persons living with dementia. The logic of this recommendation rests squarely on the potential of respite to increase or maintain caregivers’ ability to provide competent and compassionate care for the longest period of time, with the least amount of stress, burnout, and detrimental impact on caregivers’ health and well-being. Supporting caregivers in this fashion also has the potential to improve the quality of life of the person living with dementia and decrease the risk of unnecessary hospitalization or premature institutionalization of the person living with dementia.

Again, we at ARCH are grateful for the opportunity to offer this input for consideration by those planning the 2020 National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers. We look forward to attending the Summit in March 2020. Please feel free to contact Dr. Ray Kirk at rskirkassocs@gmail.com or Jill Kagan at jkagan@archrespite.org with ARCH if you need additional information.

Sincerely,

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