Prospectus for a Respite Research Funding Consortium

Introduction

This prospectus sets forth the conceptualization of an endeavor to advance an important research agenda on respite care set out in the report *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders.* The research agenda is the result of a recently concluded, 2-year study by a prestigious Expert Panel on Respite Research facilitated by the Lifespan Respite Technical Assistance Center (LRTAC) at the ARCH National Respite Network and Resource Center, with support from the U.S. Administration for Community Living. Respite was defined by the Panel 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.”

While respite is largely acknowledged to be a beneficial support to family caregivers, 85 percent of family caregivers of adults, and an equally high percentage of parents caring for children with disabilities, are not receiving respite. The Panel concluded that a stronger evidence base grounded in high quality research would help funders, policy makers and service practitioners strive to improve respite care quality, enhance access to services, and increase capacity to reach more family caregivers.

The Panel recommended assembling a Funding Consortium of public and private funders who will work together to advance the research agenda, adhering to the definition of respite care and the organizing framework for prospective research set forth in the Expert Panel’s report. Research funded by the Consortium will be rigorous, prospective, and will examine the impact of respite on caregivers, care recipients, their families, and society.

Funded research will focus on outcomes associated with improved health, well-being, and quality of life for both caregivers and care recipients as well as societal outcomes, such as avoidance of unnecessary institutional placements, delay of out-of-home placements or hospitalizations, and additional cost-effectiveness and cost/benefit analyses of respite care in public and private arenas. In addition to research that would address methodological concerns and outcomes, the Expert Panel also made extensive recommendations to improve and expand research in the areas of 1) systems change to improve access to respite services; 2) translational research to improve policy and practice; and 3) competency and training needs of respite providers. The Consortium members may consider these recommendations for funded research as well.

Vision for the Project

The vision of the Lifespan Respite Technical Assistance Center (LRTAC) for this project is to invite both established and emerging researchers with an interest in the impact of respite care to apply for research grants associated with the research agenda.

Involve researchers interested in the impact of respite care to apply for research grants; conduct meaningful, outcome-focused research; and report those findings to fellow researchers and funding Consortium members at an end-of-project summit conference.

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associated with the project, conduct meaningful, outcome-focused research within the timeframe of this project, and report those findings to their fellow researchers and Funding Consortium members at an end-of-project summit conference. The LRTAC’s vision includes funding researchers interested in a variety of respite care models, affecting a wide variety of dependent adults and children, their dependency stemming from various chronic conditions, mental health conditions, functional limitations, dementia, injury, and physical, intellectual and developmental disabilities. As the end result of this initiative, the LRTAC envisions having facilitated, along with the Consortium members, the emergence of a seminal body of high quality research studies on respite care that can be used as the basis for policy and practice considerations, and for the formulation of future outcome-focused research and efficacy testing of respite care.

**Consortium Participation**

Potential funders invited to participate in the Consortium represent a broad spectrum of organizations with interests in family caregiving and the provision of respite and other support and educational services to persons providing care to dependent adults or children. Such services are believed to be essential for the family caregiver and the care receiver to experience the best possible quality of life in the most cost-effective and cost/beneficial manner.

Invited potential funders to serve as Consortium members represent government agencies (with particular interest or responsibility in the provision of care to various dependent populations, including Veterans and military caregivers); private sector, not-for-profit foundations; private sector corporate foundations; and other philanthropic organizations. Consortium advisors will include select Expert Panel members, professional staff from the Lifespan Respite Technical Assistance Center (LRTAC), the Rosalynn Carter Institute for Caregiving (RCI), the Family Support Research and Training Center (FSRTC) at the University of Illinois in Chicago, and federal staff from the Administration for Community Living.

The maximum amount of autonomy is intended to be retained by Consortium members with respect to their primary service population definitions, including geographic, age-group, or disability/condition restrictions. Individual Consortium funders will also determine sizes and amounts of grants that may be awarded and manage grants after they are awarded. The only preconditions for participation in the Consortium are a willingness to adhere to the organizing framework presented in the Expert Panel’s final report and research agenda, and a willingness to work alongside other funders to execute a compendium of research studies to address the issues and elucidate the outcomes identified by the Panel in that report.

**Development and Dissemination of the Request for Proposals**

Immediately after forming the Consortium, the LRTAC and its advising partners—the Rosalynn Carter Institute for Caregiving (RCI) and the Family Support Research and Training Center (FSRTC) at the University of Illinois in Chicago—will work with Consortium members to develop a collaborative Request for Proposals (RFP) using the definition of respite and the organizing research framework developed by the Panel. Consortium members will specify their individual grant structure and requirements, including minimum and maximum amounts for any individual grant, overall maximum amount of funds available, traditional timelines and review processes, restrictions on eligibility for application, or specific focus of service populations or geographic areas. Potential applicants will be fully apprised during the application process, and tailor their applications to individual Consortium members in accordance with those requirements.

We anticipate a rolling review process to remain open for up to 6 months after the release of the RFP, at any time during which interested researchers may submit proposals to Consortium members. A rolling review
process is recommended because Consortium members may operate on different fiscal cycles (e.g., academic or calendar cycles).

The RFP will be disseminated in the fall or winter of 2016 to potential researchers, the Consortium members and advisors will receive and review proposals, and will make and award proposal selections according to a suggested timeline (see page 4).

Size and Types of Grants

Research grants are expected to range from doctoral research stipends intended to fund dissertation research for up to 2 years, to more comprehensive, multisite, multiyear studies conducted by established academicians and other professionals, including randomized clinical trials, if appropriate. Each Consortium member will determine the number and types of grants they are willing to contribute to the overall initiative. Using this variety of types of grants and award amounts, we hope to excite budding professionals to develop and maintain an interest in respite care research, and to excite more well-established researchers to focus on the important issues associated with the efficacy of respite care.

Who Is Eligible to Apply for Consortium Grants?

Eligible applicants who can apply for this funding include non-profit entities with 501(c)3 tax status; universities, colleges, and related research institutions; hospitals; community-based organizations; faith-based organizations; federally recognized or state recognized American Indian/Alaskan Native tribal governments; state or local governments or their Bona Fide Agents (including districts, Commonwealths, and territories of the United States). Consortium members may revise or add to this list of eligible applicants.

Proposal Review Process and Awarding of Funds

Consortium members will be able to review research proposals directed to them using their own traditional grant review criteria. Applications viewed favorably by Consortium members may also be reviewed by the professional staff at the LRTAC to assure that the organizing framework, outcome definitions, and level of scientific rigor to be employed by the researcher comport with those identified by the Expert Panel. Partnering advisors will not review the proposals as they are eligible to submit a proposal.

The Consortium member will award funds using its own grants management requirements and oversight as specified in the following section: Fiduciary Responsibility and Grants Management. From this point on, management of the grant and the accountability thereof is solely between the Consortium member awarding the funds and the fiduciary agent or office of the researcher conducting the study. We anticipate initial awards being made between early spring and late summer of 2017.

Fiduciary Responsibility and Grants Management

Neither the Lifespan Respite Technical Assistance Center nor the Administration for Community Living will assume any fiduciary role with respect to the research grants, once awarded. Rather, each grantee will interact directly with the funding source, using the funder’s accounting and grant tracking procedures.

The Lifespan Respite Technical Assistance Center, funded by the Administration for Community Living, will not be providing funds for research applicants or requesting any additional operating funds from Consortium members for its role in convening and facilitating the activities of the Consortium. The LRTAC requests only to be kept informed by each Consortium member regarding the progress of the research and preliminary findings. The LRTAC will use the information obtained from all Consortium members to develop the agenda for the End-of-Project Summit Conference (see page 4).
Communication among Consortium Members and the Lifespan Respite Technical Assistance Center

Once Consortium members have been identified and have agreed to join in the process, the Lifespan Respite Technical Assistance Center will assume the role of "information clearinghouse" for the project. The LRTAC anticipates utilizing conference calls in the initial stages of Consortium activity to begin the process of developing a coordinated Request for Proposals, and to assure coordination of Consortium members and the LRTAC.

Additional mechanisms of communication will be developed, such as a members-only section of the LRTAC’s website, to serve as a repository for announcements, updates, and requests for information. Consortium members will be notified automatically by email when anything has been posted on the website.

Summit Conference

At the end of the two to three-year research period the Lifespan Respite Technical Assistance Center will convene a summit of the researchers and Consortium member representatives to review findings, discuss practice and policy implications of the findings, and explore interest among the funders to continue the respite research initiative. The LRTAC anticipates that this will be a 1-2 day meeting, the duration being dependent to some extent on the overall number of grants awarded by Consortium members, the robustness of findings to be discussed, and the enthusiasm generated by intended attendees.

The LRTAC will be responsible for logistics associated with selection of an appropriate venue and the convening of the summit. However, the LRTAC cannot cover the costs of participants attending the summit either with respect to travel or per diem. Funds to cover participation by researchers in the summit will have been set aside by the principal investigators as part of their total budgeting responsibilities and Consortium members will be responsible for their own travel.

Project Timeline: Respite Research Consortium

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<th>Project Year</th>
<th>Activity</th>
<th>Yr 1 Q2</th>
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End Result

The emergence of a seminal body of high quality research studies on respite care that can be used as the basis for policy and practice considerations, and for the formulation of future outcome-focused research and efficacy testing of respite care.

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