

1. Cover Page

Easter Seals, Inc.
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ENHANCING COMMUNITY-BASED OPTIONS FOR END-OF-LIFE CARE

The purposes of this initiative are to improve end-of-life care for those individuals enrolled in adult day centers (and their families); to strengthen ties between the hospice community and the adult day services network at the national, state, and local level; to increase awareness within the hospice industry of adult day centers; and to establish a policy agenda addressing relevant barriers.

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2 year initiative

Total cost, \$319,724
Amount requested from Retirement Research Foundation (RRF), \$219,724

2. Summary

ENHANCING COMMUNITY-BASED OPTIONS FOR END-OF-LIFE CARE

Organization: Easter Seals, Inc.

Contacts: Jed D. Johnson & Lisa Peters Beumer

Request: \$219,724 over 2 years

Summary: The purpose of the project is to create tools and training resources to help adult day services personnel and hospice/palliative care personnel across the U.S. better understand each others roles and to enhance integration from both a clinical and programmatic perspective. We will convene a National Advisory Council with experts from both the adult day and palliative care communities to collaborate on improving end-of-life care. (A list of organizations and individuals already committed to this initiative follows.) Through providing leadership, training, and tools & materials; this initiative will enable adult day and hospice organizations to collaborate and provide more comprehensive services for people with life limiting illness and their families.

Need Statement: While a number of major initiatives have explicitly looked at end-of-life care in the long term care arena the majority of these projects, unfortunately, have not reached out to adult day providers. Many adult day centers are not equipped to handle end-of-life issues or help their clients use hospice and palliative care services. Few adult day center staff training materials address end-of-life care. (For example, the NADSA program assistant training manual, used by many adult day centers, only minimally covers the topic of end-of-life care). Many centers preclude persons with DNR orders from enrollment. Centers also report not having any programmatic mechanisms to cope with grief, loss, death and other related topics. From the perspective of hospice providers, programs often find their clients have social, respite, and daytime service needs that are not met. Many hospice staff remain unaware of adult day centers as a service delivery option or feel that these programs are inappropriate for patients enrolled in a hospice program.

Overall Objectives:

To develop and/or adapt tools that help staff integrate palliative care into adult day centers so that people who are approaching the end of their lives will have more supportive care options.

To bridge the adult day and hospice communities and encourage collaboration that will result in more comprehensive care for people at the end of their lives.

To identify barriers to collaboration between the adult day and hospice communities regarding funding, regulatory, and other issues and develop a policy agenda addressing these barriers.

National Advisory Council: Easter Seals will convene a National Advisory Council. This group will meet once per year in Chicago to advise Easter Seals on program implementation, solicit existing promising/best practice models, guide development of new tools (or modification of existing resources), review process evaluation data and benchmarks, and help identify strategies to enhance replication and sustainability. NAC participants, listed below, will also disseminate materials produced by this project to their members and encourage local chapters to collaborate with the project when relevant.

Kathy Egan, Vice President, Hospice Institute of Florida Sun Coast, Largo, FL
 Easter Seals Northern Rocky Mountain Home Care and Hospice, Butte, MT
 Horizon Hospice, Chicago, IL
 Angela Heath, Managing Director, National Adult Day Services Association (NADSA), Washington, DC
 Kathy Brandt, Vice President-Professional Leadership, Consumer and Caregiver Services, National Hospice and Palliative Care Organization (NHPCO), Alexandria, VA
 Jeanne Martinez, Palliative Care Nurses Association, Chicago, IL
 Dr. Alan Factor, University of Illinois Chicago (UIC), Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Chicago, IL
 Dr. Michael E. Preodor, Buehler Center on Aging, Northwestern University and EPEC, Chicago, IL
 Representative from Archstone Foundation's End-of-Life Initiative, Los Angeles, CA

Key policy staff from NAC member organizations will be brought together to establish a Public Policy Advisory Sub-committee. This group will be supported by Jennifer Dexter, Easter Seals Assistant Vice President for Government Relations, who handles aging and transportation policy issues for Easter Seals.

Easter Seals also has strong relationships with many other organizations with expertise and interest in this critical area, and is pleased that they have expressed a willingness to contribute to the project and serve as ad hoc members of the Advisory Council or as part of the policy advisory group. This includes:

AARP
 American Association of Homes and Services for the Aging
 American Society on Aging
 Brookdale Foundation (Group Respite Program)
 Generations United
 National Association on Area Agencies on Aging
 National Alliance for Caregivers
 U.S. Department of Veteran's Affairs

Tools & Resources: Examples of tools and resources include: an end-of-life handbook for adult day centers (pain management & other clinical protocols, sample policies and

procedures, summary of promising practice models, staff training materials and programming suggestions); a chapter to be integrated into NADSA's Program Assistant training manual; a video that could be used for either staff or consumers (note: Easter Seals is seeking funding through the Archstone Foundation for this component); a modification of UIC's curriculum on death and dying for persons with Intellectual and Developmental Disabilities; a modification of the Hospice Institute of the Florida Sun Coast's caregiver materials; an adaptation of relevant EPEC – LTC resources and tools; and training materials for hospice staff on adult day centers (introduction and definition of adult day centers, ideas for discussing adult day services (ADS) with hospice clients and families, strategies to build bridges with local ADS providers, and a sample Memorandum of Understanding).

Anticipated Outcomes: The project will foster collaboration at local, state, and national levels between the adult day and hospice provider communities. Dissemination of tools and materials will be via Easter Seals award-winning public Website, existing Easter Seals and National Advisory Council member networks, as well as through presentations at local forums, statewide gatherings and national conferences. It is estimated that the project will reach 75 Easter Seals adult day centers and an additional 1,000 centers through Easter Seals' extensive connections with state adult day associations (Note: Easter Seals headquarters staff has presented before the IL, WI, MN, IA, IN, MO, MI, OH, and numerous other state adult day associations as well as at the recent national conference in San Francisco). The initiative will reach approximately 1,000 hospice providers via Easter Seals' relationship with the National Hospice & Palliative Care Organization and local hospice organizations. At the state level, five formalized relationships will be developed between ADS and Hospice associations.

Adult Day Services organizational assessment tools will document enhanced capacity in the area of end-of-life care for individual centers. Examples of measures may include number of referrals, existence of Memorandum of Understanding with hospice provider, staff training topics, bereavement program, and nursing palliative care clinical protocols. Hospice provider organizational assessment will examine increases in awareness, collaborative activities, and referrals to adult day centers. Individual training curricula (both those newly developed as well as those that have been modified) will include evaluative components to assess changes in knowledge and practice for relevant audiences (e.g. staff, caregivers, persons served).

3. Project Significance

Importance and Relevance of the Proposed Project: No one should have to approach death without sufficient palliative support, compassion, and adequate human presence. Too many Americans experience the end of their lives with untreated pain, unaddressed depression and other mental health problems, and debilitating physical symptoms due to a lack of information and support. Family members who provide care often experience extreme emotional and physical stress without adequate support from professionals, experience economic pressures, and become ill themselves as a result of the pressing demands of caring for a loved one who is dying.

According to the U.S. Census, the number of persons age 65 and older could increase by 80% by 2025. The average life expectancy in the United States is 77 years (79 for women and 74 for men), but the largest proportional increase in population groups is those age 85 and older. With so many people approaching end-of-life, the need for direct services for individuals and families has increased. The direct service implications require new approaches, collaborations, and ideas about end-of-life care. The purpose of this proposed project is to bridge a knowledge and collaboration gap between two vital community-based services, hospice and adult day services, to better meet these end-of-life needs.

Hospice programs typically provide services in the homes of patients, supplemented where resources allow with inpatient hospice care for pain management or respite. In the course of providing holistic and comprehensive services designed to assist patients and families with all aspects of dying, hospices often find their clients have social, respite, and daytime service needs that are not met. While hospices use trained volunteers to help meet these needs, many are unable to provide enough assistance to meet all needs. Many hospice staff members are unaware of adult day centers as a service delivery or respite option. Some may feel that these programs are inappropriate or that they lack the capacity to care for patients enrolled in a hospice program.

Conversely, many adult day service centers are not equipped to handle end-of-life issues and help their clients use hospice and palliative care services. The National Study of Adult Day Services (2002) found that the second highest reason participants were discharged from adult day centers was death, yet over 80% of adult day centers reported that they do not offer hospice services (either themselves or through an affiliation with a hospice provider). While nursing care is provided at some adult day centers, palliative care may be limited because of its complexity. Few adult day center staff training materials address end-of-life issues, leaving a gap both in services for clients and in meeting the staffs' own grief and bereavement needs. For example, the National Adult Day Services Association (NADSA) program assistant training manual, used by many adult day centers, minimally covers the topic of end-of-life care. Staff training in

grief/loss or end-of-life care is not required as part of most state ADS licensing or certification processes. While the Commission on the Accreditation of Rehabilitation Facilities (CARF) adult day services (ADS) accreditation standards require annual staff training in this area, this standard is one that is often cited for non or partial conformance. Discharge summaries are also required in CARF standards as well as in many state licensing and certification guidelines. For those persons who are discharged from an adult day center due to death, rarely are any follow-up actions identified as part of this discharge summary or process. These findings, both documented and anecdotal, reinforce the need for adult day and hospice service providers to come together to build a comprehensive, caring circle of support for adult day participants at the end of their lives.

While there have been many funded initiatives in recent years that are designed to enhance end-of-life care in the long-term care arena, none have specifically targeted adult day service providers. Building on the important work of the Retirement Research Foundation, the Robert Wood Johnson Foundation, the Archstone Foundation and others, this project seeks to further these efforts within the adult day services arena.

Funding issues, regulatory requirements and other policy issues are an impediment to collaboration. This is clearly a top priority as reflected in the resolutions adopted as part of the 2005 White House Conference on Aging (WHCoA). The over 1,200 delegates to this seminal forum selected end-of-life care as priority #35, "Educate Americans on End-of-life." This project will bring together policy experts in adult day services and hospice care to identify and propose policy solutions to remove these barriers and help to move the WHCoA agenda forward.

The proposed project will design solutions for collaboration between ADS and hospice providers in the following ways:

- Convene national experts on adult day services and end-of-life to facilitate a dialogue that will result in greater collaboration
- Adapt existing training, tools, and resources on end-of-life care to increase their relevance to the adult day service setting and create new resources where needed
- Identify and disseminate promising practices on collaboration between end-of-life care and adult day services
- Develop targeted resources for hospice providers that will increase their awareness of adult day services
- Identify barriers to collaboration between hospice and adult day services and make policy recommendations to eliminate those barriers
- Develop a collaborative model that can be replicated at the state and local level

4. Statement of Objectives

The vision of this project is to enhance the end-of-life care for persons enrolled in adult day settings and their family members.

Objective 1: Increase integration of palliative care into adult day services so that people who are approaching the end of their lives will have more supportive care options.

Objective 2: Improve collaboration between the adult day and hospice communities in order to promote comprehensive and effective care for people at the end of their lives.

Objective 3: Decrease barriers to collaboration between the adult day and hospice communities through development of a policy agenda in the areas of funding, regulatory, and/or other relevant issues.

Anticipated Outcomes and Accomplishments:

- Replicable promising practices will be identified
- Adult day providers will be afforded the ability to assess their organizational capacity regarding end-of-life care
- Hospice providers will be afforded the ability to assess their awareness and utilization of adult day services
- Adult day care and hospice communities will have access to materials and training curricula that will help them provide more comprehensive services for consumers and their families coping with life limiting illness.
- Adult day center staff will have increased knowledge of end-of-life related issues from a clinical nursing, activity programming, caregiver support, and program operations perspective
- Collaboration between adult day and hospice providers will be increased at the local, state, and national levels as evidenced by establishment of formal Memorandum of Understanding

5. Description of Methodology

The proposed project will build on Easter Seals, Inc.'s experience with leading national efforts and projects, convening in-person and media-based meetings and collaborations, compiling and publishing materials based on best practices and reviewed by teams of national experts, and implementing train-the-trainer models to maximize impact of programs.

While the focus of this effort falls within RRF's model projects and service activities, this section will also incorporate the methodologies for relevant systems change and improvements in education and training.

Model Projects and Service:

Program Design:

Easter Seals has already negotiated commitments from leaders representing both the adult day services and hospice industries who will make up the National Advisory Council (NAC). These organizations are not only enthusiastic at the prospect of embarking upon this initiative, but are willing to invest significant staff time and contribute tools and materials that can be modified for this new purpose. The NAC will meet face-to-face once a year (and additionally via conference call) to advise

Easter Seals on program implementation, to solicit existing promising/best practice models, to guide development of new tools (or modification of existing resources), to review process evaluation data and benchmarks, and to help identify strategies to enhance replication and sustainability. NAC membership is outlined in the *Summary* section of this proposal.

Existing materials will be re-purposed so that they resonate with this project's target audience. This leverages RRF's support so that Easter Seals will avoid "reinventing the wheel." Where gaps are found to exist, new materials will be created. Organizations specifically providing materials to be reviewed and potentially adapted for this target audience include:

- University of Illinois at Chicago's Rehabilitation Research and Training Center on Aging with Developmental Disabilities
- National Adult Day Services Association
- National Hospice & Palliative Care Organization
- Hospice Institute of the Florida Sun Coast
- Northwestern University's Education in Palliative and End-of-life Care project

Target Audience:

- Adult day center staff, persons served and their families. Initiative will take into consideration and provide support for center-based programs of all types (respite model, social model, medical model, blended models) and serving persons with I/DD or older adults
- Hospice staff, patients and their families. Initiative will take into consideration various service delivery models whether provided in patient's home, in hospital, nursing home, or private hospice facility

Resources & Method of Delivery: Proposed tools and resources to be modified or developed include:

- Summary of promising practices (unique relationships already in-place between ADS organizations and hospice providers, tools used to address end-of-life as part of the care planning process, programming related to bereavement/grief)
- Palliative care nursing resources/protocols (pain management)
- Sample policies/procedures (DNR, referrals for hospice care, screening tools for referral for ADS)
- Caregiver support and educational materials
- Activity Programming concepts (acknowledgement of participant deaths, leaving a legacy)
- Staff training materials (ADS direct care staff, hospice staff)
- Models for collaboration between adult day services and hospice (at individual center level, at organizational level, and at state level)

A separate proposal is being submitted to the Archstone Foundation through Easter Seals Southern California to develop a 10 to 15 minute training video to supplement this project.

Once resources are developed, they will then be piloted by Easter Seals adult day services network and by Easter Seals Medallion Hospice program in Butte, MT and Horizon Hospice of Chicago. These resources will also be shared with the NAC organizations to obtain feedback. Formal dissemination external to Easter Seals will occur through educational forums held at the national and state levels, via material posted to Easter Seals and NAC member Web sites, via conference calls and web-based training, and via CDs. Refer to the *Educational Component* section for specifics regarding training for ADS staff, hospice staff, family caregivers, and persons served.

Activity Schedule and Timeline:

Refer to the Gantt chart in the *Budget & Timetable* section for an overview of project activities and quarterly timeline.

Evaluation:

Easter Seals has extensive experience conducting implementation, process and outcome evaluations to ensure programmatic success. Lisa Peters-Beumer and Jed Johnson participated in ASSERT (a training and technical assistance consultation program to build evaluation capacity amongst aging services providers) conducted through Northwestern University's Buehler Center on Aging. This project will utilize Iris Associates, the team that spearheaded the ASSERT program, as consultants to assist with the evaluation aspects of the initiative.

- At the macro-level, the NAC will systematically engage in an implementation evaluation of their efforts, making adjustments as necessary based on lessons learned over the 2 year course of funding. An evaluative component will be integrated into each face-to-face and telephonic meeting. In addition, input will be gathered from members to survey their satisfaction with group process, dynamics, sense of forward momentum, and productive use of their time.
- Organizational self-assessment tools will be developed targeting both adult day centers and hospice providers. These documents will provide individual sites and overall organizations with suggested measures to monitor progress on a longitudinal basis. It will include both qualitative and quantitative measures.

Objective	Process Indicator	Data Source	Outcome Indicator	Data Source
Increase integration of palliative care into adult day services so that people who are approaching the end of their lives will have more supportive care options.	Materials gathered and tools developed for ADS and hospice staff. ADS and hospice providers participate in training sessions. Modifications made based on feedback.	Registration forms for training sessions, feedback from session evaluations, materials ordered or downloaded from web	80% of participating adult day centers demonstrate increased capacity in the area of palliative care. 80% of participating hospices show increased awareness of ADS services. 80% of staff participating in various training modules report enhanced capacity re: end-of-life issues	Organizational assessments, pilot results, Pre- and Post-tests for respective training/curricula,
Improve collaboration between the adult day and hospice communities in order to promote comprehensive and effective care for people at the end of their lives.	NAC committee convened. Promising practices identified. Models for collaboration developed.	NAC meeting notes. Models documented.	30% increase in reported local collaborations. 15% increase in reported state level collaborations.	Organizational assessments, pilot results, MOU's developed between ADS sites and hospice providers, MOU's developed between state ADS & Hospice organizations.
Decrease barriers to collaboration between the adult day and hospice communities through development of a policy agenda in the areas of funding, regulatory, and/or other relevant issues	NAC policy sub-committee formed. Policy barriers identified.	Sub-committee notes. Policy barriers documented.	At least 5 state or federal policy recommendations made to decrease barriers. Elements of policy agenda integrated into broader policy agenda for 3 national organizations	Policy agenda for project and national organizations' policy agenda

Education Component

Target Audiences:

Through this project, Easter Seals will be targeting adult day center staff (direct care, nursing, social work, administrative, activities), persons served and their families. Materials will be individualized based on populations served (persons with I/DD, older adults, persons with dementia diagnosis). The project will also target Hospice staff (volunteers, nursing, social work, spiritual care, personal care), patients and their families.

Educational Needs to be Met:

This project intends to fill the existing gap in end of life initiatives targeting adult day service providers in order to enhance the knowledge and skills of these providers. Rectify the lack of educational initiatives that have been carried out to-date on end-of-life care to enhance the knowledge and skills of adult day service providers. An example of disconnect between the hospice and adult day communities was reflected in the 2001/2002 census of adult day centers. This survey found that the vast majority of programs (80%) do not have a formal relationship to provide hospice services. Conversely, many hospice staff members are unaware of adult day centers as a service delivery or respite option. Some feel that these programs are inappropriate or that they lack the capacity to care for patients enrolled in a hospice program, which may or may not be true.

Content/Methods/Location:

The emphasis of this project will be on the modification of existing materials to apply within the adult day setting. Materials will be tailored to respective audiences both in terms of language and examples used as well as module length. Since many adult day programs remain “low tech,” approach will be multi-faceted to accommodate a wide range of both skills and access to technology. If gaps are identified in existing resources, Easter Seals will develop appropriate training modules. Materials will be packaged into a curriculum that will be presented to provider groups such as:

- Easter Seals adult day services network
- State adult day services associations
- NHPCO conference attendees
- NADSA conference attendees
- Other NAC or ad hoc member conferences/educational forums

Evaluation:

An evaluation component using pre-test/post-test methodologies will be integrated into each curriculum. Tools will also be provided should organizations wish to measure longitudinal impact. Refer to chart in *Model Projects and Service* above.

Advocacy for Systems Change Component:

Strategies:

In year one of the project Easter Seals will research and identify policy barriers to collaboration between adult day service providers and hospice agencies. This may include funding, regulatory and other issues at the state and federal level. Information will be gathered through surveys of both adult day and hospice providers as well as interviews with national end-of-life/long-term-care policy experts. In year two of the project, Easter Seals will convene a national coalition of organizations

interested in end-of-life and adult day services to develop a shared policy agenda to eliminate the barriers identified in year one.

List of Partners:

Easter Seals will work with a broad range of organizations in developing the policy coalition. This will include policy staff from the organizations previously identified as part of the National Advisory Council as well as other leaders in the area of adult day services and end-of-life policy.

Methods for Outreach and Dissemination:

The policy agenda will be signed by all members of the coalition and the goal will be for the individual organizations to incorporate the policy agenda into their own organization's policy goals. Easter Seals will also use our online legislative advocacy center (described in *Applicant Organization* section) to disseminate information about these policy issues to activists who will then be able to communicate the importance of these issues to legislators and other decision makers. Finally, Easter Seals will disseminate information about policy barriers and the policy agenda through the Easter Seals affiliate network, Easter Seals state government relations program, existing adult day service and end-of-life coalitions, and other resources at the state level to begin addressing policy barriers to collaboration that exist the state level.

6. Dissemination

All the materials produced during this project will be published on Easter Seals Extranet for use internally by affiliate staff, and upgraded as they are used and evaluated. The materials will be disseminated as PDF files on partner Web sites, available on Easter Seals public Web site, and promoted through the newsletters and magazines of NAC members and other partners. Easter Seals adult day network coaches will continue to train peer center staff on how to incorporate end-of-life issues into their services and reach out to their state adult day services and hospice provider associations. Additional efforts will be made to connect with those ad hoc "partner" organizations highlighted in the *Summary* section of this proposal (AARP, American Association of Homes and Services for the Aging, American Society on Aging, Brookdale Foundation, Generations United, National Association on Area Agencies on Aging, National Alliance for Caregivers, and the U. S. Department of Veteran's Affairs)

The project staff along with Easter Seals' marketing, communications, and support staff will complete the following activities:

- Disseminate all materials via Easter Seals' adult day networks
- Develop and implement a dissemination strategy for each NAC member to distribute the materials
- Promote published materials to adult day and palliative care communities through national conferences, the Internet, teleconference, web-based forums and other accessible venues
- Promote and disseminate model of collaboration between state adult day and hospice associations at national conferences

Disseminate policy agenda through Easter Seals legislative action network and NAC public policy forums
 Insure sustainability through targeted training and by integrating materials into operations of Easter Seals adult day and NAC networks
 Explore additional dissemination thru ad hoc Council members identified above
 Release the video with a media campaign (if funded)

7. Budget and Timetable

Task	Year I				Year II			
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Survey and inventory existing materials and best practices from literature and adult day care and hospice care communities	■	■						
Coordinate and host first National Advisory Council (NAC) meeting in Chicago to share and review existing strategies and resources, and review and update the project plan.		■	■	■				
Develop evaluation strategy and tools		■	■					
Revise existing or create new materials to produce the following end-of-life care resources for adult day center and hospice staff End-of-life handbook for adult day centers Resource materials for hospice staff on accessing adult day services for their clients		■	■	■				
Develop a chapter for the NADSA program assistant training manual				■	■			
Conduct NAC conference call to review materials produced and advise				■				
Pilot materials developed (above) in 5 Easter Seals ADS sites, ES Highlands Hospice & Horizon Hospice				■	■			
Revise the materials based on NAC and Easter Seals' adult day pilot site feedback and evaluation.					■	■		
Develop models of collaboration between state adult day and hospice associations using the materials developed in goal one				■	■			
Identify target states for collaboration between state adult day associations and state hospice associations					■			
Conduct conference call for state associations to introduce model of collaboration between state adult day and hospice associations						■	■	

both adult day services and hospice care throughout this entire project (NADSA and NHPCO).

RRF is familiar with the success of Easter Seals' peer-to-peer, mentorship-based approach to improve service delivery across all of our adult day centers. This proven model will again form the foundation for quality improvement across our entire network, this time focusing on end-of-life care.

Easter Seals has strong communication and operational structures in place internally, and maintains strong connections with external state and national stakeholders. Templates for collaboration between adult day and hospice providers at the individual center-level, organizational-level, and state level will provide the basis for ongoing dissemination and replication. Easter Seals will actively support other entities (state adult day associations, large multi-site providers, state units on aging, etc.) should they wish to build upon these efforts and further the objectives outlined in this proposal.

9. Personnel

Lisa Peters-Beumer, MPH-Project Director and Marketing Manager/Senior Community Service Employment Program

Ms. Peters Beumer has been working in the field of long term care for over 12 years, primarily in the areas of dementia care, health promotion & wellness, hospice care, senior mobility, and most recently senior employment. Her work has addressed a variety of both clinical and policy related issues among the aging population. She holds a Masters in Public Health from Northwestern University and joined Easter Seals at its national headquarters in December of 2001 to head up the AoA-funded Transportation Solutions for Caregivers project. Immediately prior to coming to Easter Seals, she worked for Horizon Hospice in Chicago for over 3 years. She has presented at numerous state, local, national, and international conferences and is actively involved with the American Association on Aging's Network on Environment, Services & Technologies for Maximizing Independence.

Jed D. Johnson MBA, MSW-Project Supervisor and Assistant Vice President/Adult and Senior Services

For the past 6 ½ years, Mr. Johnson has provided leadership and support to Easter Seals branches across the U.S. in the area of Adult Day Services and senior services in general. Easter Seals is the largest provider of adult day services in the nation with over 70 centers in 24 different states. He also plays a leadership role for Easter Seals Transportation Solutions for Caregivers project funded through the Administration on Aging's National Family Caregiver Support Program and the Retirement Research Foundation. Prior to

working for Easter Seals, he was with the Jewish Association on Aging in Pittsburgh where he was vice president of home and community services. This included four adult day services sites, a hospice program, home delivered meals, outreach in Naturally Occurring Retirement Communities, a PACE program, Information & Referral, home health & private duty services. In addition to serving on the Board of Directors for the local Alzheimer's Association chapter, he also served on other local and statewide organizational boards. At the national level, he is former chair of the National Adult Day Services Association (NADSA), was a member of the CARF Board of Trustees and now sits on their International Advisory Committee and conducts accreditation surveys in the area of Aging Services. He is a member of both the program committee and the shared site advisory committee for Generations United and is a member of the National MS Society's Long Term Care Advisory Board. He recently joined the Board of the American Society on Aging. His areas of expertise include grant administration (federal, state, and foundation), collaboration/joint ventures, as well as diversity issues. He holds a joint-masters degree in social work from the University of Pennsylvania's School of Social Work and business administration from the Wharton School of Business. He is a frequent speaker at local, state, regional, national, and international forums.

Jennifer Dexter, BA-Project Advisory/Public Policy and Assistant Vice President/Government Relations

Ms. Dexter has been with Easter Seals Office of Public Affairs for 10 years. In her role, she leads Easter Seals' efforts to create and strengthen public policy affecting adult and senior services, rural residents with disabilities, assistive technology, telecommunications, and housing for people with disabilities. She also works with Congress annually to assure funding for Easter Seals' two Federal programs, AgrAbility and Project ACTION. Prior to joining Easter Seals in 1996, Jennifer was a research/legislative specialist for the American Academy of Child and Adolescent Psychiatry. Jennifer received her B.A. in political science from Washington University in St. Louis in 1992. She has been a member of the National Adult Day Services Association board of directors and continues as a member of their Policy Committee. Ms. Dexter is actively involved with the Consortium for Citizens with Disabilities and has chaired a variety of committees/task forces related to transportation, aging, and assistive technology.

Iris Associates-Project Consultants

Madelyn Iris received her Ph.D. in Anthropology from Northwestern University. She has additional training in focus group facilitation and in program evaluation. Dr. Iris is the founder of Iris Associates, a woman-owned sole proprietorship specializing in social program evaluation and organizational evaluation capacity building. Dr. Iris has worked as an independent research and evaluation consultant in the field of aging for over twenty year, in a variety of social service settings. Among her areas of expertise are: protective services (elder abuse and self neglect), aging services, self care, family caregiving, dementia and Alzheimer's disease. Dr. Iris was the Director of ASSERT, a training and

technical assistance consultation program to build evaluation capacity amongst human service providers.

Rebecca Berman received her Ph.D. in Anthropology from Northwestern University as part of Northwestern University's Program in Ethnography and Public Policy, with an emphasis on organizational culture. She has received additional training in evaluation methods from the Evaluator's Institute. Dr. Berman has worked as an independent research and evaluation consultant in the field of aging since 1987 in a variety of social service settings. As a Research Assistant Professor at the Buehler Center on Aging, she was also the Co-Director of ASSERT, a training and technical assistance consultation program to build evaluation capacity amongst service providers.

10. Applicant Organization

Easter Seals has more than 85 years of experience serving people with disabilities and their families. We are well positioned to help our affiliates and the NAC members' impact communities throughout the country. In addition to being the nation's largest provider of adult day services, Easter Seals is trusted by the more than one million people we serve and their families. Nationally, we have over 80 affiliates and more than 550 service sites and years of experience marketing services to communities.

In 2001, with support from the Retirement Research Foundation, Easter Seals shaped and institutionalized emerging experience in providing adult day services and created a national Adult Day Services Network. Using successful network models, such as the peer to peer mentorship model developed by the Robert Wood Johnson Foundation's Partners in Caregiving program, Easter Seals has been able to expand its adult day network to over 70 centers covering 24 states in just six years. Easter Seals recently brought to a close a multi-year project focused on provision of support to caregivers and adult day providers in the area of transportation. Sponsored by the Administration on Aging and RRF, Easter Seals produced and distributed nearly 3,000 toolkits to aging and transportation organizations across the United States, reaching an estimated 25,000 caregivers and aging network personnel.

Easter Seals national staff includes experts in adult day services, marketing, public relations, public affairs, and business management. Our Web site functions as an integrated network combining affiliate, program, and event sites throughout the country. Visited by over 55,224 unique visitors monthly, our headquarters site was recently named one of the "Top Nonprofit Web Sites" nationally by The Nonprofit Times. All of these resources will be used to ensure the success and continuation of this program.

Easter Seals maintains a legislative action center on the Easter Seals Web site <http://www.easterseals.com>. This section is designed to provide the general public with information about public policy issues affecting people with disabilities and seniors and to spur them to action through on-line action alerts that provide them with messages and a means to communicate directly with their members of Congress. In addition, over

11,000 people receive a legislative newsletter from Easter Seals that highlights issues of immediate importance.

Our experience in both the service-delivery and policy arenas gives us great insight and skill supporting and advocating for persons with age related disability and loss of function and in helping family members cope with stress associated with caring for their loved ones. In addition, through the RRF funded Local Transportation Solutions for Seniors project and other national initiatives, Easter Seals has successfully developed practical, replicable solutions to complex issues facing seniors and their families and disseminating those solutions to both internal and external stakeholders. We are in a unique position to facilitate collaboration between adult day and palliative care/hospice service providers to offer a more comprehensive approach to end-of-life services.

A copy of Easter Seals 2006 audited financial statements and 2005-2006 annual report are attached.

11. Tax Exempt Status

Easter Seals, Inc. is tax exempt under Section 501 (c)(3) of the Internal Revenue Code. A copy of the organization's IRS determination letter classifying our organization as "not a private foundation" under Section 509 (a) of the Internal Revenue Code is attached. Easter Seals' 501(c)(3) classification and the "not a private foundation" status has not been revoked or modified.

Easter Seals Retirement Research Foundation Grant Proposal

Budget Category	Year 1	Year 2	Total RRF
Personnel	\$47,531	\$48,957	\$96,488
Personnel	\$47,531	\$48,957	\$96,488
Fringe Benefits	\$16,089	\$16,572	\$32,661
FICA	\$3,636	\$3,745	\$7,381
Worker's Compensation	\$238	\$245	\$482
Unemployment Insurance	\$238	\$245	\$482
Medical/Dental	\$3,850	\$3,966	\$7,816
Retirement/Pension	\$6,940	\$7,148	\$14,087
Other	\$1,188	\$1,224	\$2,412
Travel	\$8,850	\$12,450	\$21,300
Travel for NAC	\$6,600	\$7,200	\$12,800
Travel for Staff/Conference Registration	\$3,000	\$5,000	\$8,000
Travel for local staff/NAC members/Policy Advisory Sub-committee	\$250	\$250	\$500
Contractual	\$10,000	\$24,000	\$34,000
Consultants	\$10,000	\$24,000	\$34,000
Other	\$2,000	\$13,300	\$15,300
Printing & Publication	\$0	\$10,000	\$10,000
Events & Meetings	\$1,800	\$1,800	\$3,600
Misc. Postage, Phone & Web Site	\$200	\$1,500	\$1,700
Total Direct Charges	\$84,470	\$115,279	\$199,749
Indirect Charges	\$8,447	\$11,528	\$19,975
Indirect Charges - 10% of Total Direct Charges	\$8,447	\$11,528	\$19,975
RRF COST	\$92,917	\$126,807	\$219,724

Easter Seals staff time & related expenses for Project Supervisor and Project Advisor-Public Policy represent an in-kind contribution to the grant.

Foundation grant proposal (Video) with Easter Seals Southern California & CAADS

\$25,000
\$75,000
TOTAL Project \$319,724

Enhancing Community-based Options for End-of-Life Care
 Easter Seals Headquarters
 Budget Narrative

Budget Category
Personnel
Personnel: Overall project management Total Easter Seals headquarters staff = 128 FTE's
Fringe Benefits
FICA Worker's Compensation Unemployment Insurance Medical/Dental Retirement/Pension Other
Travel
Travel for NAC (\$800 per trip for airfare, ground transportation, hotel) YR 1 x 7 members; YR 2 x 9 members Travel for Staff/Conference Registration (American Association of Homes & Services for the Aging/National Adult Day Services Association, National Hospice & Palliative Care Organization; American Society on Aging/National Council on Aging) YR 2 up to 5 conferences Travel for local staff/NAC members/Policy Advisory Sub-committee (ground transportation) YR 1: Travel to visit promising practice sites x 3
Contractual
Consultant YR 1: (honorarium for NAC members providing materials to be adapted \$8000; evaluation work with Iris Associates \$2000) YR 2: (honorarium for NAC members \$ 8000. Evaluation work with Iris Associates \$2000. Design/layout/materials development \$12,000)
Other
Printing & Publication (training materials, tools, and resources) Events & Meetings (NAC face-to-face mtg., Policy Advisory Sub-committee mtg.) Misc. Postage, Phone & Web Site
Indirect Charges
Indirect Charges - 10% of Total Direct Charges
In-Kind Contributions

Easter Seals staff time & related expenses for Project Supervisor and Project Advisor-Public Policy represent an in-kind contribution to the grant.

Foundation grant proposal (Video) with Easter Seals Southern California & CAADS