THE RETIREMENT RESEARCH FOUNDATION

GRANT HIGHLIGHTS

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Horizon Hospice Prepares Rush University Medical Center for New Inpatient Hospice Unit

In July 2012, Horizon Hospice & Palliative Care opened a 13-bed inpatient hospice unit at Rush University Medical Center. This is the first nonprofit inpatient hospice unit within a major teaching hospital in Chicago. Horizon was awarded a one-year, $60,192 grant to educate Rush clinical and non-clinical personnel in preparation for the opening of the new unit. The objectives were to: 1) create an understanding and a culture of comfort care within the Rush system; 2) assist Rush staff to understand the unique interdisciplinary nature and value of hospice; and 3) improve communication between Rush personnel and patients and their families regarding hospice care. Horizon expected the training to increase the number of appropriate referrals to the new inpatient hospice unit as well as to its home-based hospice program.

Horizon held 70 in-person trainings for physician, nursing, social work, and other clinical and non-clinical departments. Trainings were conducted by Horizonôs President and CEO, its Director of Clinical Education, and Rushôs Director of Palliative Care, who also serves as Horizonôs Inpatient Medical Director. An independent consultant and another palliative care physician provided a few additional presentations to small physician and healthcare professional groups. In total, 1,764 Rush employees were trained, including nearly 600 physicians and other medical staff. Several additional nursing unit trainings were scheduled to be conducted after the grant ended.

In addition to the in-person trainings, Horizon developed online educational modules. The first is for physicians and the second (ñHospice 101ò) is for other clinical and non-clinical personnel. After initial feedback, Horizon created a third module specifically for nurses because of the need for more clinical detail. These modules are loaded on the Rush platforms. In late 2013, more than 50 medical fellows and residents took the first online physician training.

Horizon administered pre- and post-training tests. Ninety percent showed improvements in knowledge of hospice and palliative care philosophy and practices. However, many participants were reluctant to take the tests. While respondents showed improvement in knowledge, the percentage of accuracy was still low, especially in the area of pain management (improvement from 54 percent to 63 percent). Several recommendations for additional training and re-training are under consideration.

Horizon created several training tools. They include a patient care booklet specifically geared to the inpatient unit, a brochure, PowerPoint presentations, and a laminated card with admission criteria.

Since the educational sessions were launched, Horizon has seen a steady increase in referrals to the inpatient hospice unit. In the first 15 months, more than 500 patients were admitted, with 334 during the last eight-month period. Nearly half of the referrals came from Rush. One-third came from the Horizon home care program. Seventeen area hospitals have made referrals. Horizon has also seen record enrollment in its home-based hospice program.

Horizon reported a cautious approach by physicians in referring to the inpatient unit. Changes in the healthcare environment and federal concerns about fraud and abuse seemed to add to the atmosphere of caution. To meet this challenge, Horizon created a handout on Medicare guidelines for acute care and conducted several additional small group meetings with key physicians to explain admission requirements.

Horizonôs report described the challenge of scheduling and carving out sufficient training time for very busy units. But, Horizon has been tenacious and has even planned booster training. It has also reached out to area hospitals in strategic ways. It conducted a four-week pilot with the University of Illinois Hospital (UI) to test policies for patient transfers from UI Hospital to the Horizon inpatient hospice unit. The policies have continued to enhance transfers and may serve as a model to be used with other hospitals. In addition, the Horizon Inpatient Medical Director introduced the inpatient hospice to Loyola University Medical Center at its grand rounds.

This project has reconfirmed the need for training and re-training on palliative and hospice care. Many myths and misunderstandings pose barriers to appropriate referrals for inpatient hospice care. The project also emphasized the need to equip clinicians with the skills to introduce and facilitate end-of-life conversations and combat the discomfort that many individuals have around these issues.

Two Houses of Worship Make Accessibility Improvements

During the last few months, two Chicago-area houses of worship improved their facilitiesô accessibility with support from RRFôs Accessible Faith Grant Program.

Carter Temple Christian Methodist Episcopal Church is a large, African American, relatively low-income congregation in Chicagoôs South Shore neighborhood. Older adults are nearly one-third of this 2,760-member congregation. The church conducts many activities that engage its older members, including a large Missionary Society, and sponsors many community programs. It hosts monthly meetings of the Aldermanic Office and several social and health promotion activities.

In 2011, Carter Temple received a $30,000 Accessible Faith Grant to install two platform lifts and a short modular ramp to provide access to the facilityôs worship, social, and educational areas. Prior to the grant, there was no vertical accessibility between levels of the building. This prevented many members and visitors from participating in activities.

The congregation conducted a survey of its members prior to applying for an Accessible Faith Grant. Thirty-seven percent of the respondents indicated they had a

disability themselves or had a family member with a disability. Although the church had previously installed chairlifts, they were inadequate and unsafe.

Now that the platform lifts and the new ramp are in operation and accessibility has improved, the pastor has begun discussions with the churchôs Commission on Aging Ministry on a plan to engage senior assisted living facilities in the area. The church recently hosted a luncheon for 150 seniors, in partnership with the 6th Ward Aldermanôs Office. This could not have been done without the accessibility improvements.

St. Louis de Monfort Church is a 3,300-member Roman Catholic parish in Oak Lawn. Sixty percent of its members are seniors. In its application for an Accessible Faith Grant, the pastor indicted that participation by older adults was diminishing because of the churchôs poor sound system. There are many musical programs in addition to the worship services that could not be fully appreciated.

With a $7,155 Accessible Faith Grant, the church installed a new assistive listening system. The project even came in slightly under budget. A new and improved product was found at a slightly lower cost than originally projected. The system includes eight assistive listening devices with earphones, ear buds, and T-coils. The pastor included several articles in the bulletin describing the advantages of the new system and its proper use.

The pastor indicated that when the new system was powered up, he was ñshocked to hear the improved quality of the sound.ò Parishioners have remarked, ñIt is a real blessing to be able to hear every word very clearly.ò

Colorado Frontier Regions Receive Palliative Care Education

In 2011, RRF awarded a 16-month, $33,494 grant to Life Quality Institute (LQI), a Denver-based, independent educational institution, to provide palliative care education to healthcare professionals in five of Coloradoôs frontier regions. A frontier region is defined as one with low population density; geographic barriers such as mountainous terrain; sparse or small market-service centers; far-flung, sometimes inadequately equipped medical facilities staffed by a thinning and aging healthcare professional community; aging residents whose adult children have moved out of the area; technological challenges such as inadequate cellphone or Internet service; and limited local philanthropic resources.

LQI had been delivering palliative care educational programs in the Denver area for a number of years and was well known and respected by healthcare professionals in the area. However, it had not yet expanded its reach to the frontier areas. RRF funding enabled LQI to develop a three-day, educational program on palliative care, entitled ñPrepare 2 Care,ò and deliver it to five frontier regions. The target audience included physicians, nurses, social workers, chaplains, care managers, counselors, and adult protection workers.

LQI began with a needs assessment in each region in order to tailor the educational presentations. The needs assessments showed similar interests in all regions: the need to emphasize pain and symptom management; mental health and mental illness in palliative care; spiritual needs; and grief and bereavement issues. In each region, LQI collaborated with a healthcare provider, usually a hospice or hospital that was responsible primarily for promoting and hosting the sessions. LQI conducted pre- and post-workshop evaluations and conducted follow-up surveys to determine the effect of training on clinical behavior. It also developed strategies to sustain the educational programs after the grant.

During the initial 16-month grant, LQI conducted the three-day program in four of the five regions but needed additional time to complete the fifth. The additional time also enabled LQI to revise and test alternate formats (including both in-person and webinar) and consolidate the workshops into a more intensive certificate program format. It was able to test these in the fifth region and conduct a second round in two of the more successful regions.

All of the programs received very high ratings (at least 4.5 on a 5-point scale). A variety of professionals attended, including nurses, RN students and CNAs, volunteers, social workers, chaplains, and others. They came primarily from hospices, hospitals, universities, and community colleges. Nurses represented 40 percent of all attendees. Physicians represented only five percent. It was probably unrealistic to expect physicians to dedicate so much time to the training, especially in the first round when there was no webinar format as an alternative.

A total of 338 people attended the programs. An additional 130 attended the two second-round programs run during the extension. Forty percent attended by webinar and 60 percent in person.

LQI measured knowledge gains through pre- and post-session tests. Average increases in learning were high--from 15 percent to 24 percent. Notably, nearly all test-takers failed the pre-test (scoring lower than 80 percent). Almost all passed the post-test on the first attempt. LQI tried to gauge the impact of its program on participantsô clinical and caregiving practices. It used electronic surveys and followed up with mailed surveys. However, the response rate was low even after LQI shortened the time frame for follow-up from three months to one month. However, even with small numbers, responses were consistent in a few areas. The session on total pain and symptom management seemed to have the most influence on changes in clinical behavior. The session on the ethics of dying was also noted by many respondents as important in changing their behavior.

LQI drew several conclusions from its educational experience that will influence the future structure of its educational programs and the selection of partners. It will also incorporate feedback from its presentation at the annual statewide Colorado Center for Hospice and Palliative Care Conference. LQI has decided to deliver the training in more of a certificate format rather than in the form of discrete workshops. This will enable LQI to present more information in a concentrated time frame rather than spreading out the educational programs. LQI will partner with the Area Health

Education Centers because of their strong outreach capacity. LQI will make greater use of webinars.

This project emphasized the challenges of delivering cost-effective educational programs in rural/frontier areas. Adding to the challenge is the fact that palliative care is still misunderstood and meets with resistance. Creative structuring, along with strong partnerships, will be needed to implement a sustainable model of education on palliative care in remote areas.

HOME Builds Marketing and Communications Capacity

In 2011, RRF awarded a $51,459 grant to Housing Opportunities and Maintenance for the Elderly (HOME) to develop and begin implementing a marketing and communications plan. The purpose of this organizational capacity building (OCB) project was to increase HOMEôs visibility and recognition as an innovative program model for older adults. The ultimate goal was to enable HOME to secure additional funding to expand and sustain its services for the elderly.

RRF funding enabled HOME to engage a consultant to develop a formal marketing and communications plan. HOME was able to revamp its website; create a new logo to reflect its core message; and design, print, and distribute new marketing materials such as brochures, an annual report, and new letterhead. The grant also enabled HOME to purchase and begin using new marketing software to enhance electronic communication and online marketing efforts.

HOME met or exceeded nearly all of its objectives. Its marketing efforts contributed to a 15 percent increase in the number of major donors, thus exceeding the 10 percent goal. It increased the number of new donors by 49 percent, far exceeding the 10 percent goal. HOMEôs website visitors increased by 10 percent, which was slightly lower than the 15 percent goal. Its presence on social media grew considerably; Facebook connections rose from 40 people to 80, and its Twitter following grew from two to 138 people.

HOME chose to take advantage of the organizational coaching RRF offers in conjunction with OCB grants. Its Executive Director reported having an excellent experience with coaching. He said, ñThe coach provided insight, suggestions, and support that were valuable to me in my role as Executive Director but also to HOME as an organization.ò He said, ñGiven the positive experience with HOME and the critical support offered through the coach, perhaps the Foundation could consider offering this service to all grantees.ò

Hanul Builds Human Resource Management Capacity

In 2011, RRF awarded a $47,775 organizational capacity building grant to Hanul Family Alliance to develop more effective approaches to human resource (HR) management. Hanul, originally named the Korean American Senior Center, operates a large home care program for homebound elderly. It serves nearly 8,000 seniors annually.

Prior to receiving the OCB grant, Hanul had engaged in an RRF-funded organizational assessment to help set priorities for capacity building. It recognized the need to take a more strategic look at how it uses, evaluates, and compensates its staff. If it were to remain ñlean, mean, and sustainable,ò it needed the right staff in the right functions. Hanul realized it needed a process for assessing staff performance more systematically.

RRF funds enabled Hanul to engage an HR consultant to guide the review and the development of new HR tools. Funding also supported costs associated with translation services to allow Hanul employees who spoke limited English and were more comfortable with Korean to participate in the project.

Hanul successfully achieved all of its project goals and reported a very positive experience with the consultant. Confidential interviews were conducted with 55 employees, including all of Hanulôs professional staff and most home care aides. Ten members of the Board were also interviewed. Hanul held staff and Board retreats for group reflection. The consultant incorporated insights from the interviews, retreats, and an audit of agency documents into a report with a series of recommendations.

Following Board and senior staff discussions about the reportôs recommendations, the agency undertook several action steps. It completely revised the employee handbook with updated HR procedures and processes to clarify expectations across all levels of the organization. The handbook was legally accurate and consistent with HR best practices. Hanul conducted trainings and small group discussions about the new handbook with all staff to clarify new procedures and promote open discussion. Hanulôs staffing structure was revised, and a Deputy Executive Director was designated as HR liaison. This created a central hub for HR functions and decisions.

Job descriptions were revised to reflect key roles and responsibilities more accurately. Gaps in the staffing structure and necessary additions were identified. A performance management system was put into place. This will allow for standardized and regularly scheduled performance reviews and facilitate staff feedback in a more systematic manner.

Hanul began investing in professional development for top managers. Its four director-level staff enrolled in Axelson Centerôs Nonprofit Management Certificate Program at North Park University. This was partially supported by RRF funds, as an additional feature of the OCB Program. Hanul developed a relationship with the HR Director of a more established ethnic service provider to gain an understanding of how HR practices are carried out in a similar, although larger, nonprofit. The project is leading to impressive transformations for this very important agency.

Mindfulness Training Shows Promise for Reducing Stress for Patients with Early State Alzheimer's and Their Caregivers

In 2011, RRF awarded an 18-month, $54,316 grant to Northwestern University to conduct a pilot test on the impact of mindfulness training to reduce stress for persons with early Alzheimerôs disease and their caregivers. Mindfulness involves daily meditation; concentrated visualization directed at relaxing images, and cognitive retraining to teach people to adapt better to stressful situations.

The study suggested that mindfulness training could be helpful for persons with early Alzheimerôs disease because the techniques work on implicit memory, i.e.,

building up a tendency in the brain to adopt a mindful approach to life that becomes unconscious. Implicitly held memories are not lost until the later stages of Alzheimerôs disease.

The investigators proposed to enroll 48 subjects--24 caregiver/patient pairs. Twelve pairs were to be randomly assigned to the mindfulness training and the other 12 to a control condition. The intervention was to consist of a 90-minute class each week for eight weeks. The active control intervention was to include support groups involving both caregivers and persons with early stage Alzheimerôs disease, offered through Northwesternôs Alzheimerôs Disease Research Center. The investigators planned to gather post-treatment and longer-term, follow-up data on outcomes.

The investigator trained 37 individuals in mindfulness. However, not all were dyads. Twenty were caregivers and 17 were persons with early stage dementia, (not all were of the Alzheimerôs type). Instead of a randomized methodology, the investigator ran two back-to-back, pre-post studies on participants with the same characteristics. The first group tested change over time resulting from mindfulness, and the second tested change over time from a cognitive retraining intervention, which acts on working memory as opposed to implicit memory. This methodology allowed the investigator to control for Hawthorne effects or for the possibility that participating in a group activity could in and of itself impact outcomes of interest that were independent of the mindfulness training.

The same measures were gathered for both groups. They included depression, quality of life, sleep quality, anxiety, caregiver distress, activities of daily living function for the patients, and caregiver health. Cognitive tests were also conducted. The mindfulness training group (both patients and caregivers) showed significant improvement over time on quality of life. There was slightly more improvement for patients than caregivers. There was also significant improvement in depression scores. There were no changes in sleep quality, anxiety, caregiver distress, or in activities of daily living function as rated by caregivers. There was significant improvement in caregiver physical and emotional health as shown on the SF 36. For the cognitive retraining group, there was no significant improvement over time on any measures.

The study was presented in the *Journal of Cognitive Neuroscience* (January 2013). The study suggests that mindfulness training may have the potential to assist both persons with early stage dementia and their caregivers. However, further research is needed to test the method in a more rigorous way on a larger sample.

Palliative Care Training Program Developed for Chaplains

In 2011, RRF awarded a $75,000 grant to Healthcare Chaplaincy, Inc. (HCC) to develop a national specialty training program that would lead to certification as a Palliative Care Chaplain. At the time of the grant, chaplaincy was the only profession among those represented on most palliative care teams that did not have a training program for specialty certification in palliative care.

The projectôs objectives were to identify and specify the competencies necessary for a fully-trained palliative care chaplain and develop curricula for clinical pastor educators and Board-certified chaplains wishing to prepare for specialty certification in palliative care. The plan was to train 50 Board-certified chaplains and 25 clinical pastor educators and conduct pre- and post-testing to determine what the participants learned and how it affected their practice. The plan also called for creating a process to certify

palliative care chaplains that would be nationally recognized in palliative care communities and in chaplaincy care.

At the beginning of the project, HCC surveyed palliative care chaplains, doctors, nurses, social workers, and others working in palliative care settings to determine the importance of various competencies. Thirty-five competencies were identified. Rather than reinvent the wheel, HCC developed a 10-module course, adapting materials from two existing, internationally-recognized curricula--EPECare (developed by Dr. Linda Emanuel at Northwestern Universityôs Buehler Center on Aging) and ELNEC, the End-of-Life Nursing Education Consortium. The 10 modules include: 1) History and Philosophy of Palliative Care; 2) Spiritual, Existential and Emotional Issues; 3) Family Systems and Group Facilitation; 4) Chaplain as Spiritual Leader on the Palliative Care Team; 5) Ethics and Common Palliative Care Issues; 6) Social and Cultural Influences on Palliative Care; 7) Chaplain Leadership as Mentorship; 8) Ethical/Critical Reasoning Using Cases; 9) Professional Wellness while Working in Palliative Care; and 10) Palliative Care: Science and Religion Together Again. Each module features leading national palliative care experts from a variety of professions, including nursing, social work, medicine, and chaplaincy.

The course uses a distance learning format that blends real-time live sessions with asynchronous online learning materials. It was first offered through HCCôs Online Learning Center. Seventy-five students provided feedback in the pilot testing of the course. The participants indicated they highly valued the learning experience but made a number of suggestions. As a result, HCC made revisions, including greater use of case studies and more opportunity for direct personal engagement with speakers.

HCC has now completed course refinements. It has also ensured the course will be offered on an ongoing basis as a university-based, professional certificate program through its partnership with California State Universityôs Institute of Palliative Care. Cal State will offer the palliative care course with formal certification. HCC provides the content, and Cal State provides the learning management system. HCC expects that 150 people will participate in the program annually over three semesters.

HCC also worked over a nine-month period with the Association of Professional Chaplains to gain its approval of a sub-specialty certification in palliative care. The certification process is scheduled to begin in January 2014. This is very significant because it is the first time the Association has approved a sub-specialty certification of any kind. HCCôs unique curriculum is a major step forward in ensuring high-quality, professional spiritual care for patients and their families in palliative care settings.

Web Hurley Endowment Benefits Palm Beach County Elders

In 2008, RRF honored long-time Trustee, Webster Hurley, by awarding funds for an endowment in his name at the Mental Health Association of Palm Beach County (MHA). Throughout his tenure as a Trustee, Web Hurley had been a supporter of MHAôs work with community partners to prevent mental health disorders and improve understanding about issues related to mental health and well-being.

Through the Webster H. Hurley Endowment for Senior Programs, MHA offers several education activities and support groups that target older community members. MHA also has a service navigator/information service that fields more than 500 calls annually; approximately eight percent of the callers are seniors. MHA indicated that many of these calls reflect struggles with the stress and anxiety of an uncertain economy, health issues, and other concerns. Callers can receive free basic needs screenings, confidential mental health screenings by licensed mental health professionals, and referrals to local mental health and social service providers. A large percentage of the calls are from family caregivers or service providers that make inquiries on behalf the elderly. MHAôs online resource center has a special section for older adults.

In 2012-13, MHA produced a new series on aging which included examples of events of special interest to older adults. They covered topics such as the effects of trauma on older adults, depression, restoring balance, and building resiliency, mindfulness, and self-compassion. The legacy of Trustee Hurley lives on as the endowment continues to benefit Palm Beach County elders and their families.

Policy Corner I: New Requirements Issued for Medicaid Home and Community Based Services

Section 1915(c) of the Social Security Act authorizes the Secretary of Health and Human Services to waive certain requirements of the Medicaid law in order for states to provide Medicaid Home and Community Based Services (known as HCBS) to meet the needs of individuals who choose to receive their long-term care services and supports in their home or community, rather than in institutional settings. In January 2014, the U.S. Department of Health and Human Services/Centers for Medicare and Medicaid Services (CMS) issued the final ruling that established new requirements for HCBS. The final ruling is the culmination of several years of an extensive rulemaking process and reflects significant gathering of public comment.

The final ruling makes several important changes to the 1915(c) HCBS waiver program. It requires that HCBS settings meet certain qualifications to be eligible for Medicaid reimbursements. HCBS settings must be integrated in and support full access to the greater community; be selected by consumer choice from among setting options; ensure individual rights of privacy, dignity, and respect, and freedom from coercion and restraint; optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them.

The final rule permits, but does not require, states to combine target groups (older adults and individuals with various disabilities) within one HCBS waiver as long as the states assure their ability to meet the unique services needs of individuals in each target group and that each individual in the waiver has equal access to all needed services. There will be a transitional period during which states will need to ensure that their waivers and plans meet the new requirements.

The final ruling also mandates that service planning for participants in 1915(c) Medicaid HCBS programs be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals.

RRFôs trusted grantees, including the Consumer Voice for Long-Term Care and the Make Medicare Work Coalition, are in the process of analyzing the regulations and the impact of the final ruling on long-term care consumers. We shall share these analyses with the Trustees.

Policy Corner II: Medicare Policy Manuals Reflect *Jimmo vs. Sebelius* Case Settlement on Need for Improvement

In 2011, RRFôs grantee, the Center for Medicare Advocacy, challenged the Medicare systemôs widespread use of an improper ñimprovement standardò when determining medical necessity for skilled nursing services and outpatient therapy. Although the improvement standard had never been supported by the Medicare statute or regulations, Medicare contractors applied the improvement standard inappropriately to deny or discontinue care. The Center for Medicare Advocacy brought a law suit against the Centers for Medicare and Medicaid Services (CMS), claiming that the improvement standard violated Medicare law and deprived beneficiaries of care they needed to maintain their existing conditions and prevent or limit deterioration.

The Center for Medicare Advocacy won a federal court settlement that required CMS to take corrective actions. As a result, CMS recently updated its Medicare Policy Manuals to make it clear that improvement is not necessary for coverage of skilled nursing and therapy services. Examples of the changes in the Manual include the home health section, which now states, ñCoverage of skilled nursing care or therapy to perform a maintenance program does not turn on the presence or absence of a patientôs potential for improvement from the nursing care or therapy, but rather on the patientôs need for skilled care. Skilled care may be necessary to improve a patientôs current condition, to maintain the patientôs current condition, to prevent or slow further deterioration of the patientôs condition.ò

The settlement agreement also requires CMS to conduct an educational campaign for providers and consumers. CMS has complied by releasing a fact sheet and Medicare Learning Network Article and hosting a national call for providers. It will soon host an Open Door Forum on the manual revisions.

The *Jimmo* agreement applies to both Medicare Advantage as well as the traditional Medicare program. It applies to any beneficiary who requires skilled services to maintain a condition or to prevent or slow deterioration regardless of the underlying illness, disability, or injury. It also applies to skilled maintenance services provided in all three care settings under Medicare Home Health, outpatient therapy, and skilled nursing facility benefits. The Center for Medicare Advocacy will continue to monitor CMS compliance with the settlement and with application of the law.

Note: *RRF staff takes much of the information for GrantBriefs directly from grantees' final reports. Staff often asks questions and holds discussions with grantees to get a more complete understanding of the results of grants and to understand challenges grantees faced. While we encourage candor, we recognize that grantees tend to report results in the most positive way.*