

Pension Rights Center Expands Pension Assistance

In 2014, RRF awarded a third-year grant of \$75,000 to the Pension Rights Center in support of the National Pension Assistance Resource Center (NPARC). RRF funds served as a match for the Administration of Community Living/Administration on Aging funding. NPARC provides legal training, technical assistance, and outreach to a network of seven regional pension counseling projects, covering 30 states. In addition to providing legal training for the counseling sites, NPARC promotes knowledge-sharing and best practices among the projects, expands the availability of pension assistance beyond the 30 states covered by federal funds, provides direct assistance on complex cases, and advocates to protect pension coverage.

During the grant period, the counseling projects collectively recovered \$15 million in pension benefits, while assisting 3,000 clients. In total, since the program's inception 21 years ago, the counseling projects have recovered more than \$206 million in benefits for primarily low- and moderate-income clients. More than 50,000 individuals have received assistance.

During the grant period, NPARC continued to deliver high-quality training through an annual three-day national conference, attended by all pension counseling attorneys from all sites. In addition to training on substantive topics and skills such as legal writing, the conference emphasized relationship-building with officials from key government agencies with whom the sites typically interact (e.g., the Internal Revenue Service, Pension Benefit Guaranty Corporation, and the Social Security Administration). NPARC also encouraged shared-learning through its interactive listserv and a protected website where projects share useful documents for representing clients. NPARC expanded its database to include 5,800 pension plans. The listserv covered more than 90 topics during the grant period.

NPARC reached out to legal service providers in states not covered by the pension counseling projects. It conducted webinars and in-person presentations for legal service providers in Georgia, Florida, Maryland, and Washington, DC. It also conducted trainings for the U.S. Department of Labor's (DOL) regional offices in Maryland and Pennsylvania. The DOL trainings brought in \$13,000 and may become a steadier source of revenue for NPARC, if DOL contracts with NPARC for training all DOL regional offices. NPARC has developed a catalog of available trainings and course materials. As a result of expanded training, more cases were referred to NPARC and the counseling sites, and NPARC was able to add to its *pro bono* network of attorneys who handle cases outside the 30 states covered by the pension projects.

During the grant period, the Pension Rights Center improved its website and communications, which incorporates NPARC's information. Website traffic doubled,

compared to the previous year. There were nearly 440,000 visitors; 81 percent were new to the site.

NPARC advocated for the establishment of a Lost Pension Plan Registry within the Pension Benefit Guaranty Corporation (PBGC). A provision authorizing the Registry was included in tax extender legislation at the end of the last Congressional session. However, time ran out before a vote on the legislation could occur. A few months ago, the Pension Rights Center met with the Acting Director of PBGC. The U.S. General Accounting Office, the Department of Labor ERISA Advisory Council, and PBGC's Participant and Plan Sponsor Advocate (a new position created as a result of PRC's advocacy efforts) have all recommended that PBGC establish the Registry. Hopefully, the Registry will be authorized in 2015 since it is neither controversial nor expensive.

The issue of recoupment continued to be a focus of NPARC's advocacy. When an error causes a plan to overpay in pension benefits, it often institutes recoupment to recover overpayment plus interest. Usually, the beneficiary has been totally unaware of the erroneous overpayment. NPARC staff and representatives from the counseling sites met with the IRS Associate General Counsel for Employee Benefits to share cases of clients harmed by unfair recoupment practices. As a result, the IRS issued new guidelines stating that it will no longer require plans to recover overpayments from overpaid plan participants. Instead, plans may seek repayment from other sources. The IRS invited public comment on this practice. The Associate General Counsel publicly stated that she would not have known about the harmful effects of recoupment practices had she not participated in the discussion with the counseling project attorneys. Although the IRS guidelines do not have any teeth to them, they do put pressure on plans to take alternative measures or suffer public ill will.

NPARC has faced the challenge of finding staff with sufficient legal experience in the highly technical area of pension law. As a nonprofit, NPARC finds it difficult to compete with commercial firms because of the lower salary level it can offer. It has met immediate staffing needs by using law students and recent law school graduates as interns. NPARC hopes to bring them up to speed with intensive training and create a pool from which to draw. NPARC has also expanded recruitment of Fellows, retirees who are very experienced in the pension area, to provide technical assistance to the pension counseling sites. It has a corps of six Fellows and has identified another six it hopes to recruit during the next year.

Milwaukee's Seniors Gain Access to Public Benefits

In 2013, a \$15,346 grant was awarded to the Social Development Foundation of Milwaukee as second-year support for a benefits access program. The Social Development Foundation served as the fiscal agent for the Social Development Commission and Senior Companion Benefits Enrollment Program. The purpose of the program is to raise awareness of public benefit resources for low-income older adults and help them overcome obstacles to enrolling in benefits.

RRF funds supported a part-time Benefits Enrollment Specialist. The grantee was able to reduce the position from .8 FTE in the first year to .4 FTE in the second year because it trained volunteers and solidified partnerships to assist with the work.

The project's activities included outreach events to inform elders about public benefits, individual screenings to determine eligibility, and enrollment assistance to help seniors file applications. Two online tools, Benefits CheckUp and Wisconsin Access, were used to screen and complete applications.

The grantee provided educational materials at group presentations and sent mailings to at least 1,000 seniors. It screened 300 seniors through in-person meetings at its offices and at partner sites in the community. As a result of screenings, 246 seniors were found to be eligible for benefits. The project's staff and volunteers enrolled all qualifying seniors into benefits programs--far exceeding the projected enrollment of 100. The estimated value in benefits secured for eligible seniors was \$460,000.

Staff and volunteers attempted to contact 140 prior program participants to ensure that they had successfully renewed their benefits. Ultimately, after several follow-up calls, they reached 100 prior participants and assisted those who needed help with renewals and applications for additional benefits.

Brown University Studies Financial Implications of Culture Change in Nursing Homes

In 2013, RRF awarded a one-year, \$83,757 grant to Brown University to study financial factors related to the uptake and outcomes of culture change in nursing homes. Culture change is the transformation from an institutional approach to care delivery to one that is person-centered, i.e., where each person's capabilities and individuality are affirmed and celebrated. In culture change, quality of care and quality of life are inseparable and equally important (as defined by the Pioneer Network). The study was a follow-up to the first large national survey of nursing home culture change adoption, which Brown University conducted from 2008-2011, with a three-year, \$289,435 RRF grant. The survey measured adoption of specific practices within central domains of culture change and included a sample of 4,149 nursing homes. The research found that 85 percent of facilities interviewed reported some level of culture change practice. The study indicated the importance of financial factors, both in the uptake and outcomes of culture change efforts; however, they were not explored in depth at that time.

With RRF funding, Brown University's team examined how finances of nursing homes drive facilities to adopt culture change and, in turn, how culture changes influence facility profits or financial well-being. The research involved merging existing data with two federal datasets that Brown purchased. The first is the Medicare Cost Report, which details nursing home payment levels and sources. The second is the Online Survey, Certification and Reporting data (OSCAR), which has data on facility size, staffing, bed availability, survey deficiencies, and patient severity of illness. Analysis involved the use of logistic regression to identify the set of variables

contributing to the relationship between baseline net revenue per bed and level of culture change adoption.

The study found that culture change had no financial impact on nursing homes in terms of cost savings or expense. Facilities with higher levels of culture change did not show statistically significant increases in income over expense, compared to lower-adopting homes, nor did their income over expenses decline significantly.

The researchers are preparing a paper that describes the methodology used to compile the cost report data for the study. They hope that, by sharing the very complex and time-consuming methodology for their work, they will shorten the process for other researchers who may wish to use this data. The project will be presented at the Gerontological Society of America's annual meeting this fall. Results are also being shared through a Brown University listserv of 3,000 long-term care professionals and researchers and papers are being prepared for publication.

It is difficult to predict whether, or to what extent, this study will affect the level at which nursing homes will adopt culture change. On one hand, nursing homes could become less enthusiastic about culture change because it was not found to have a positive effect on financial well-being. On the other hand, the study could allay fears that investing in culture change will incur huge costs.

Pioneer Network Shares Culture Change Lessons

In 2013, RRF awarded a second-year grant of \$139,008 to the Pioneer Network in Culture Change to identify, compile, and share strategies for implementing person-centered care in nursing homes. This was the second phase of a collaborative learning project through which the Pioneer Network engaged nursing homes in implementing four essential person-centered care practices: 1) consistent assignment of direct care staff; 2) communication during shift changes; 3) involvement of nursing assistants in care planning conferences; and 4) involvement of direct care staff in quality improvement. In the first phase, the Pioneer Network engaged 240 nursing homes from 10 states. The nursing homes viewed training videos, which were followed by one-time discussion with the nursing home staff about methods for implementing what they learned. Forty-nine facilities participated in more intensive learning, which included webinars on each of the four practices, followed by monthly calls to share implementation experiences. Ninety percent of these facilities provided pre- and post-test data rating themselves on improvements in quality of care in important arenas such as use of antipsychotics, falls, and pressure ulcers.

The second phase of the project involved an implementation evaluation to capture in greater detail the lessons learned during the earlier training and compiling them into a manual. By doing so, the Pioneer Network hopes to make it easier for a large number of nursing home providers across the nation to benefit from the efforts of the homes that participated successfully in the project's first phase.

The Pioneer Network conducted case studies on 21 %incubator+ homes, slightly exceeding the goal of 20. It worked collaboratively with experts who had been involved

in the first phase to conduct site visits to the facilities. Assessment of the 21 nursing homes focused on their experiences implementing the four practices, clinical indicators of success, and tools developed by these facilities. The methods of evaluation were extremely thorough, and the final report included forms used for site visits, questions, probes, and the pre-site visit questionnaire.

The Pioneer Network produced the *Handbook for Engaging Staff in Individualizing Care*, which synthesizes the experiences of the 21 participating nursing homes. It focuses on the four central practices of person-centered care by defining them, describing their importance, and providing implementation steps. The handbook includes video clips, tools, and tips for implementation. It can be purchased online as a five-part webinar series in DVD format.

In addition, the Pioneer Network created a *Communication Map for Engaging Staff in Individualizing Care*, which provides both organizational- and individual-level guides to assist with implementation. It is available online at no cost. The webinar series and communication map can be found on the Pioneer Network's website at <http://www.pioneer-network.net/>.

Dissemination of the project's findings and announcement of the handbook have been extensive. The Pioneer Network presented a webinar for 80 Quality Improvement Organization representatives and conducted sessions at the Pioneer Network annual conference, attended by more than 75 individuals. It also presented at the annual conference of the National Consumer Voice. The Pioneer Network sent an email blast to 11,000 contacts upon release of the handbook.

These grant products are the long-term result of early research on culture change, funded by RRF some thirty years ago. Despite laws and recommendations on culture change which have been put into effect, nursing homes seem to have difficulty implementing these changes. Practical guides to evaluate and aid implementation are essential to continuing efforts to make quality of life and care better for nursing home residents.

Track and Trigger Treatment Protocol Found Effective in Improving Drug Use for Nursing Home Residents

In 2013, RRF awarded a one-year, \$54,558 grant to the University of Wisconsin-Milwaukee to test a protocol to stop ineffective and unneeded drug treatments for nursing home residents with dementia. The protocol, previously developed by the grantee, addresses the common problem of administering treatments that are ineffective, no longer needed, associated with side effects, or inconsistent with goals of care.

The Track and Trigger Treatment Protocol (T^3) is initiated when a new treatment is started or an existing drug or non-drug treatment is altered. T^3 consists of a series of assessments of physical and behavioral symptoms in which any of four events triggers the nurse to consult with the prescriber regarding stopping, altering, or replacing the

treatment. The triggers go off when either: 1) treatment is ineffective; 2) there are side effects; 3) the problem is resolved; or 4) treatment goals have changed. Nurses are taught to collect observational information from CNAs daily. CNAs work closely with residents so they are most likely to observe changes in behavior or conditions.

RRF funding supported further testing of T³. The goal of the project was to refine the forms and processes and compare the protocol to usual care to determine differences in quality and cost of care. Eight matched units from two nursing homes were randomized to T³ Protocol or usual care. Nurse managers were trained to use the T³ Protocol and document the process on tracking forms. Nurses were taught to document their usual evaluation of treatment response on tracking forms. Weekly feedback on ways to improve the forms and T³ processes were solicited, and changes were made based on feedback. Nurses completed a 19-item feasibility survey and a post-test survey in the last week of their participation. There were 37 residents in the treatment group and 41 in the control group. There were no significant differences between the groups in any demographic variables.

Overall, the T³ Protocol was found to be effective in getting a greater number of treatments stopped and improving assessment quality. During an eight-week period, nursing home residents in the T³ Protocol group had an average of 8.14 treatments stopped, compared to 5.76 in the usual care group. Treatments were stopped because of ineffectiveness (33 percent), problem resolution (29 percent), change in care goals (20 percent), and side effects (18 percent). During a 40-day period, the T³ group received an average of 39 assessments, compared to 36 in the control group. The Protocol led to more person-centered, non-drug communication treatments (e.g., cueing, education, and therapeutic communication), which are important to quality of care and life for nursing home residents.

Scores for items measuring ease of use and usefulness of the T³ Protocol were high. One of the nurses commented that the Protocol was a great help in communicating with physicians, although their unwillingness to trust a nursing assessment was perceived as a barrier to getting treatments stopped.

The T³ Protocol was found to save costs as well. Drugs stopped in the treatment group during the eight-week period saved a median of more than \$34 per resident, compared to nearly \$14 per resident in the control group.

The research team presented the project's findings at the 2015 Midwest Nursing Research Conference and the 2014 Gerontological Society of America's annual meeting. The team plans to present again at the 2015 GSA meeting. Two manuscripts have been submitted to nursing journals.

While the project provided evidence that the T³ Protocol changes assessment quality and care delivered, the study did not examine the effect on resident outcomes. Next steps involve a larger study of the effectiveness of the T³ Protocol on care, cost, and resident outcomes, and testing an electronic version.

National Hospice & Palliative Care Organization Develops Patient Perception of Care Survey

RRF awarded a two-year, \$214,726 grant to the National Hospice & Palliative Care Organization (NHPCO) to develop a standardized patient perception of care survey tool. Hospice and palliative care providers could use the tool to evaluate the quality of care from the perspective of the patient with a life-limiting disease.

There has been a growing emphasis on quality assessment in healthcare. Although there are performance measures that utilize patient reports of their experience with care for hospitals, home care agencies, and clinician groups, no such tool was previously available for hospices.

Although this project took nine years to complete, it resulted in the development of a survey tool, known as the Assessment of Patient Perception of Care, which was administered by 23 hospices to more than 1,900 patients receiving care in their home settings. The project included: 1) identification of concepts related to hospice care that are important to measure; 2) development of survey questions and response options based on the concepts; 3) cognitive testing, involving administering survey questions and discussing them with patients to ensure questions would be interpreted as intended; 4) field testing on patients; and 5) analysis, involving a series of statistical tests to investigate the scientific soundness of the survey tool. The analysis focused on validity (is the tool measuring what it is intended to measure?) and reliability (are survey question answers consistent across respondents?).

The hospice version of the survey resulted in a viable quality of care measure that is now available for hospices to use for quality improvement efforts. The use of the tool will also allow for comparison of the quality of patient-centered care across hospice providers. However, data submitted for the palliative care version of the survey were insufficient for appropriate statistical testing. More data collection is needed to evaluate this version fully and to move ahead with wider dissemination.

Earlier this year, NHPCO met with the Centers for Medicare and Medicaid Services and MedPAC to share information on the Assessment of Patient Perception of Care survey. The tool will be in the public domain and soon will be available, along with other performance measures listed on NHPCO's website. This project will contribute significantly to the field by providing an assessment tool that can be used by hospices for quality improvement and by the Centers for Medicare & Medicaid Services, as well as consumers, as a means of comparing hospices.

Update on Six Accessible Faith Grants

St. Gregory the Great is located in Chicago's Edgewater community. It is a Roman Catholic parish with nearly 1,400 members. Thirty-five percent of the parish membership is age 65 or older. The parish is diverse, with a large percentage of Asian/Filipinos. It hosts many well-attended fellowship events as well as musical concerts and dance performances.

Most of the activities occur in the lower-level meeting area of the gym building. With a \$30,000 Accessible Faith grant, the parish was able to construct an ADA-compliant ramp and entry-way to provide easier access from the sidewalk to the lower level of the building.

The project's budget increased from \$119,800 to \$125,400 due to a revision of the entry-way directly into the social gathering hall. During construction, asbestos tiles were found and had to be removed. Soil testing was done to determine further contamination. Fortunately, none was found.

The parish held a well-attended dedication for the ramp. Many elders have begun using the ramp to attend events, and a few who had dropped out of activities, have already returned. The project director reported that many mothers of young children have also expressed appreciation for the ramp because its universal design makes handling strollers easier.

The parish has been advertising its accessibility on the electronic sign outside the building and informing groups of the new improvements to encourage greater use of the facility. Recognizing the importance of inclusion, the parish is now planning to make its bathrooms ADA-accessible.

St. Matthew Lutheran Church and School of the Missouri Synod is located in Hawthorn Woods (Lake County). It has nearly 1,500 members. One-third of its membership is age 65 or older. St. Matthew Church engages its members in a wide variety of fellowship and worship activities. The facility is also an emergency center for the Villages of Hawthorn Woods and Lake Zurich because it has a kitchen on the lower level and large rooms on the second level that can be used to shelter people overnight.

Prior to receiving a \$30,000 Accessible Faith grant, St. Matthew Lutheran Church had no vertical accessibility within its building to access either the upper or lower levels, thus limiting use for many of its members. The project involved installing an elevator to allow access to all three levels.

The project was successfully completed, nearly 12 months ahead of the 18-month schedule. The cost came in slightly below the projected budget of \$225,000. The project was well managed and involved members of the congregation in tasks such as minor painting, which reduced costs slightly.

In his final report, the project manager stated, "The elevator project brought our congregation together. A successful financial campaign, participation from our service organizations, and several willing worker projects brought joy and harmony of individuals that have never worked together but yet attended the same worship service. The congregation has begun to work with its synodical connections, government, and local service organizations to encourage use of its newly-accessible facility."

St. Pius X Parish is a large, 7,000-member Roman Catholic Church, located in Lombard (DuPage County). Eleven percent of its membership is age 65 or older. The parish is diverse, with a large Hispanic membership. The church hosts many fellowship activities, a monthly senior group, and a large food pantry.

Prior to receiving a \$30,000 Accessible Faith grant, St. Pius X Parish had no accessible restrooms in its facility. The project involved constructing two new accessible, double-occupancy restrooms.

The project was successfully completed ahead of schedule. Although there were a few additional costs, such as installation of emergency lights to comply with village codes, the project still managed to stay within its \$87,000 budget.

The project was timely because it coincided with the parish's 60th anniversary. Several large celebratory events occurred in conjunction with the anniversary and provided an opportunity for parishioners to see the project's progress during construction. The project's visibility helped emphasize the importance of inclusion and boosted fundraising. More than 200 families made financial contributions to the project.

The final report included many positive comments by parishioners. They expressed their appreciation for the ability to be more independent, the beautiful design of the new restrooms, and the convenience of not having to wait in a long line to use them.

Greater Bethesda Missionary Baptist Church (MBC) is located on Chicago's southeast side in a historic structure. It is a 162-member, African American congregation. Nearly two-thirds of its membership is age 65 or older. In addition to several spiritual and fellowship activities for older adults, the church offers its facility to many community groups and is a venue for concerts by the National Association of Negro Musicians and Morehouse College.

In 2010, RRF awarded a \$25,000 Accessible Faith grant to Greater Bethesda MBC for a two-phase project. Phase one included construction of a ramp to create an accessible entrance. Phase two involved making an existing restroom near the entrance accessible.

Phase one, construction of the ramp, was successfully completed although the plan had to be revised significantly. The original design called for construction of the ramp at the Michigan Avenue entrance and replacement of a hazardous, deteriorated sidewalk. However, after further consultation with its architects, an alternative plan was devised to construct the ramp on the 53rd Street side of the building to fit better with the historic structure. Revisions included modifications to accommodate higher elevation and construction of a "switchback" ramp. The City of Chicago also required modifications such as the removal of a small roof, a new set of exterior entrance doors, additional handrails. The cost increased by one-third to nearly \$78,500.

Greater Bethesda MBC shared many examples of ways in which the congregation and community have been benefiting from the ramp. The church's senior group has already increased its membership (although the number was not provided). The church has hosted several denominational events, and in the process, provided an opportunity for the church to raise the issue of accessibility to a broader audience. Due to significant structural problems with the building, the church has had to delay completion of phase two.

Uptown Baptist Church is a 114-member Southern Baptist congregation serving a primarily low-income, African American population. Sixteen percent of the membership is age 65 or older. Although it has a relatively small membership, Uptown Baptist is a significant resource to the community, especially to older adults. It operates a large soup kitchen and is a distribution site for the Greater Chicago Food Depository. It also serves as shelter and provides office space for Illinois Shelter & Recovery Services.

Prior to receiving a \$30,000 Accessible Faith grant, Uptown Baptist's facility had no accessible entrances. Congregants sometimes carried people up and down the stairs to get into the building. Some soup kitchen attendees had to be served on the sidewalk because they could not enter the inaccessible building. The congregation recognized that this situation was dangerous, inappropriate, and an affront to people's dignity.

With AFG support, Uptown Baptist installed a three-story elevator to provide an accessible entrance and access to the basement and main floor. The project was completed slightly ahead of schedule and at only \$2,000 over the \$320,000 budget. A few modifications had to be made such as integrating the smoke and fire alarm systems into the main system and widening the elevator shaft to accommodate caskets.

Now that Uptown Baptist has improved accessibility within its facility, the church leadership has begun to connect with the Salvation Army to reach out to the organization's retirement community and encourage participation in some of its activities.