Morville House, one of the properties housing SHARE clients.

COMMUNITY INNOVATIONS FOR AGING IN PLACE (CIAIP) GRANTEE CASE STUDY

SHARE: SERVICES TO HELP AT RISK ELDERS

A PROJECT OF
THE ELDERS LIVING AT HOME PROGRAM (ELAHP)
BOSTON MEDICAL CENTER

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BACKGROUND

The increasing population of older Americans necessitates an expansion in programs and services that are responsive to their priorities and needs.[1-3] Given the challenges of independent living for those with suboptimal health and/or functioning, programs that facilitate aging in place represent an important component of a responsive service system.[4] Such programs remain novel,[5] with much to be learned at both the local and national level—including identification of best practices for direct service delivery, as well as approaches that promote systemic solutions and community-wide changes.

Community Innovations for Aging in Place (CIAIP) was funded from 2009 to 2012 by the United States Administration on Aging (AoA) in response to the need for systemic and integrated responses to shifting demographics. Through CIAIP, demonstration projects were funded in fourteen sites around the country. In addition, the Center for Home Care Policy and Research (CHCPR) of the Visiting Nurse Service of New York (VNSNY) was chosen as the Technical Assistance Grantee (TAG), which included VNSNY staff and consultants, to provide training and other supports focused around program design, program implementation, communication, and evaluation (see Table 1 for listing of grantees.)

Table 1: CIAIP Grantees

CIAIP Grantees
Atlanta Regional Commission, Atlanta, GA
Boston Medical Center, Boston, MA
Catholic Charities, Kansas City, MO
Catholic Charities, Stockton, CA
City of Montpelier, VT
The Coordinating Center, Millersville, MD
Easter Seals New Hampshire, Inc., Manchester, NH
Family Eldercare, Austin, TX
Jewish Family Service of New Mexico, Albuquerque, NM
L.A. Gay and Lesbian Center, Los Angeles, CA
Mt. Sanford Tribal Consortium, Gakona, AK
Neighborhood Centers, Inc. Bellaire, TX
New York City Department for the Aging, New York, NY
Supportive Women's Network, Philadelphia, PA
Center for Home Care Policy & Research, VNSNY (TAG)

This case study report is one in a series of case studies developed by the TAG. The case studies describe program models, challenges, and lessons learned for organizations and funders seeking to develop aging in place programs, as well as others with interest in the topic. Data for this and other case studies was gathered primarily through site visits and in-person interviews and discussions with program staff and stakeholders.* Depending on the site, stakeholders included some combination of clients, partners, Advisory Board members, and community members with interest and expertise

* The data collection was approved by the Institutional Review Board of The New York Academy of Medicine, a member of the VNSNY TAG.

in issues related to aging in place. Additional information came from reviews of program documents including project proposals, reports, and outreach materials.

CIAIP grantees developed a range of program models and specific services. For the purpose of the case studies, these models and services could have been grouped and categorized along a number of dimensions. The framework we utilized focuses on a grantee's overall approach and delineates five overarching themes:

1. Broad based community development and planning
2. Service provision in settings where older people live and congregate
3. Building bridges across program and organizational "silos"
4. Mobilizing human and social capital through volunteering and advocacy
5. Reaching out to and engaging specific groups of overlooked or disenfranchised older adults

Services to Help at Risk Elders (SHARE), a project of the Elders Living at Home Program (ELAHP) at Boston Medical Center, is an example of the fifth listed approach. SHARE assists formerly homeless older adults, as well as those at risk of homelessness, to remain stably housed through comprehensive, individualized, and ongoing case management and nursing services provided during home visits and in other community settings. SHARE targets the most vulnerable of older adults. Besides living in poverty, clients commonly have significant physical and mental health issues, minimal independent living skills, and inadequate social support systems. The SHARE program is being evaluated by John Snow, Inc. The evaluation includes tracking of frequency, type and length of visits; open-ended client interviews; and individual baseline and follow-up assessments of overall health, mental health, nutrition, food security, physical activity, alcohol consumption, medication adherence, hygiene, and social connectivity.

HOMELESSNESS AND OLDER ADULTS

With the aging of the general population, the number of older adults that are homeless or unstably housed has also been growing.[6] Compared to other older adults, those that are homeless are more likely to have chronic illnesses, including diabetes, hypertension, cardiovascular disease, and cancer,[6,7] as well as limitations in performing activities of daily living.[6] In addition, they have disproportionately high rates of mental illness, cognitive

impairment, and alcohol and other substance use [6,8,9] and are significantly more likely than other at-risk populations to be socially isolated.[9-11] Not surprisingly, poverty, lack of insurance, psychosocial issues, and competing priorities limit access to and utilization of needed services by homeless populations.[6,8,10]

The traditional model for homeless services expects individuals to move through a continuum of care, which (for example) may include drug treatment and transitional housing. Prior to placement in permanent housing, clients must demonstrate "readiness," through abstinence from drugs and alcohol, adherence to medical recommendations, and/or mastery of independent living skills.[12] In contrast, a "Housing First" approach—like the one used by SHARE—assumes housing as the primary need and that housing accompanied by supportive services can effectively prevent future episodes of homelessness.[13-15]

In a Housing First approach, clients are required to comply with a standard lease agreement; utilization of particular services and/or behavioral changes, however, are not mandatory.[15] The Housing First approach appears particularly appropriate for certain older adults, including the long-term homeless and those with cognitive difficulties, who are unlikely to make the behavior changes assumed in the traditional model. In fact, housing provided with supportive services, has been shown to promote residential stability, improve health service use, improve health outcomes, and reduce societal costs.[6,16] However, there is little publicly available descriptive information on the implementation of supportive programs targeting older adults. This case study reporting on SHARE may in part fill this gap by providing detailed information on program implementation, outcomes, challenges, and lessons learned.

PROGRAM DESCRIPTION

Services to Help at Risk Elders (SHARE) is a project of the Elders Living at Home Program (ELAHP) at Boston Medical Center. Since its inception in 1986, ELAHP has assisted homeless older adults to find and maintain emergency shelter and long term housing. Recognizing that a portion of their clients required ongoing stabilization and health-related services, SHARE was developed under the ELAHP umbrella to provide more comprehensive, individualized, and ongoing case management and nursing services. With a caseload of approximately forty, SHARE direct service staff includes two full-time case managers, one part-time case manager, and a part-time registered

nurse (RN). SHARE clients live in subsidized housing, where program staff collaborate with Resident Service Coordinators, other building staff, and other community organizations to provide a supportive environment for residents. In fact, connections to health care for the homeless programs, senior centers, food programs, philanthropies, and others are considered essential to meet the full range of client needs.

Upon enrollment, SHARE clients agree to a service plan that includes a baseline assessment and regular visits from both the RN and a case manager. SHARE staff see clients as often as required (and wherever required)—sometimes multiple times per week. Length of visits varies. Nurse visits are usually less than one hour; case manager visits, in contrast, may be two hours. Issues addressed during SHARE visits include:

1. Management of health conditions, including the provision of health education and medication management
2. Accessing needed medical and supportive services
3. Nutrition assessment and education
4. Money management, banking, and bill payment
5. Accessing food
6. Social support

Depending on the individual, staff may serve as liaisons to health care providers, family members, and housing staff, advocating for services, mediating disagreements, and "interpreting" discrepant expectations.

Approximately 50% of SHARE clients have been chronically homeless for a significant portion of their adult lives. According to baseline evaluation data, close to half rated their health as something less than "good;" 32% sometimes worried about insufficient funds to purchase food; and 58% reported binge drinking in the 30 days prior to the assessment. Just half of SHARE clients shopped for groceries, prepared meals, and managed their finances alone.[17] James*, for example, was housed through ELHAP and is now a SHARE client. He has been a heavy drinker for many years:

> *I used to live in Southie. There was a fire in the house and they were doing the house over and then they decided they were going to make condominiums out of it. So, I was out on the streets. I was sleeping on Commonwealth Avenue, and the truck used to go by every night and one night they*

* Pseudonyms are used throughout the report.

told me, "You have to go in [to the shelter], because it was below zero." I said, "You woke me up to tell me it was below zero?" Then we got to be friends and they helped me to get this place.

Yvette, another SHARE client, is an immigrant, who had been employed as a domestic worker. Her children live overseas; she has other family in Boston that she sees regularly, but they lack the resources to house her or to provide her with support on a daily basis. Yvette came to SHARE through a homeless shelter. Although her independent living skills are adequate, she has needed ongoing assistance from SHARE to better manage her diabetes and other health issues.

ACCOMPLISHMENTS

Some two years into implementation, SHARE staff, collaborators, and clients were able to delineate a number of successes, including high satisfaction with program services. James, the client brought in off the street when the temperature was below zero, commented: "I call them my family. God bless them. I love them, to be truthful with you." Evaluation findings (comparing years 1 and 2 of the project) reported by John Snow, Inc. suggest increased consumption of fruits and vegetables, reductions in binge drinking, improved hygiene, and better social integration. Accomplishments reported during the TAG site visit—as described below—focused on housing stability, health, food security, and knowledge regarding service delivery for this very high need population.

Housing Stability

A notable accomplishment of SHARE is that no clients have been evicted or returned to unstable living conditions:

Speaking as a management company, it's a great resource because it's expensive to move somebody in and do a turnover on an apartment. And this way people are staying longer than they probably would have.... We don't do evictions very often. It's very, very extreme. But, I could easily see some of these people getting an eviction notice if they weren't hooked up in this way. (Resident Services Coordinator in subsidized housing)

SHARE clients, in fact, face a wide range of issues that may impact on housing stability, including competing priorities resulting from low or no income, poorly managed health conditions, and substance abuse. As described below, if these priorities are not addressed, clients will not have funds available to pay rent on a regular basis. SHARE clients, like all tenants, must also learn the rules of independent living, which may be a particular challenge for those who lived on the streets or in shelters for extended time periods:

> *When you look at people who maybe don't know how to take care of their apartment and the manager is saying, 'This apartment is a pigsty.' ... Even general housekeeping, like fire hazards on the stove. In their mind, they're not using the stove. What does it matter if newspapers are there? (Resident Services Coordinator in subsidized housing)*

SHARE staff have helped to mediate eviction notices and reconcile the sometime conflicting priorities and concerns of management and clients, particularly around housekeeping and potential safety hazards, as noted above. They have also helped clients manage their money in a way that limits their ability to drink to excess, helped with the forms and paperwork necessary for uninterrupted enrollment in entitlement programs, and helped them to purchase money orders used for rent payment. Among all SHARE clients, the only housing changes that have occurred resulted from interpersonal issues (one client was moved to other subsidized housing) and deteriorating cognitive abilities (two clients were moved to assisted living facilities).

Health

A large number of SHARE clients have chronic health conditions, including conditions that are newly diagnosed and/or newly treated at program entry. Clients must learn basic information about these illnesses, their management, and their treatment. The SHARE RN is essential to this process, meeting with clients at enrollment and as needed (but no less than quarterly) thereafter. Home visits allow the RN to assess food access, dietary behavior, and medication management, as well as health literacy and language issues. Diabetes is particularly prevalent and challenging for SHARE clients, as they may lack a conventional schedule, sufficient financial resources, and knowledge and skills regarding disease management—as suggested by the RN in the following anecdotes:

We had a gentleman... and I was trying to figure out what's going on with his blood sugars and sometimes people just assume that everybody eats dinner at five or that everybody eats... So they would say, "Take your insulin around dinner time, you know, five o'clock." [But] he wasn't eating until nine.

This woman [Yvette, described above], it sounded like she was doing everything right. And, I'm like, "Jeez, this isn't making any sense." I don't even know why [she's] diabetic, and she's eating fish and she eats oatmeal. And then [during a home visit] out of the corner of my eye: six teaspoons of sugar I saw go into her tea... and there was my answer.

Home visits represent only a portion of SHARE health-related activities. By accompanying clients on physician visits, the RN and SHARE case managers are also able to serve as patient navigators and advocates, reinforcing medical recommendations, and working with clients to access appropriate medical services. Yvette, for example, had difficulty managing her medications. The SHARE RN could not see her as frequently as needed so an attempt was made to connect her with a visiting nurse. The services of a visiting nurse, however, would also be time limited, with self-sufficiency as the required objective. Recognizing that self-sufficiency was very likely unattainable, SHARE connected Yvette to a nearby Senior Center that offered on-site nursing services on a regular and ongoing basis. They also connected her to a local doctor whose approach to diabetes management was more consistent with best practice recommendations, as compared to her previous provider. As a result of these changes—and a reduction in the amount of sugar she puts in her tea—Yvette's blood glucose level has dropped from 800 to 200 (or less), she feels better, and her doctor has observed improved kidney functioning. SHARE staff have also facilitated access to surgery for esophageal cancer for one client and surgery for the removal of cataracts for another. "It was biblical," the latter reported. "I was blind and then I could see."

SHARE staff also provides needed information to physicians regarding client comprehension of medical information, medication adherence, and appropriate expectations. They report that clients are very reticent with doctors and will neglect to ask even pre-identified questions. Having a SHARE staff member at the visit facilitates a significantly more

comprehensive exchange of information and quicker progress.

Food Security

SHARE has identified food access as a critical issue for clients. In fact, close to 45% of case manager referrals are to food pantries. According to a member of the SHARE administrative staff:

> *Stability in housing depends on health. It also depends on food. Because if somebody has a very low income…they're more apt to pay their rent if they have money to buy food*.

In fact, quantity and quality of food are both significant concerns. Some 20% of SHARE clients have health issues, such as diabetes, that require a specialized diet, yet many face barriers to proper nutrition. These barriers include minimal financial resources (as noted above), as well as limited mobility (due to disability and/or transit issues), inadequate knowledge, and poor food habits. The RN, describing one of the SHARE clients, explained:

> *And I found cookies and jelly—orange crush in his refrigerator. But, he's another with limited funding, so [he eats] whatever he gets from the food pantry.*

The consequences of these food barriers were evident in blood glucose levels of diabetic clients, and the fear was irreversible deteriorations in health, necessitating placement in assisted living facilities. In response, SHARE developed collaborations with local organizations that provide free meals and free food. Case managers collect and distribute selected healthy food from pantries, including fresh fruit and vegetables, to clients on a biweekly basis. These are very labor intensive activities with complicated logistics. SHARE therefore applied for and was awarded a two-year, $225,000 grant from AARP to support and expand its food access program, which includes a nutritional needs assessment, food "prescriptions" and shopping lists, home delivery, nutritional education, and repeated biometric and nutritional assessments. The food access program, a collaboration with Boston Medical Center's Center for Endocrinology, Nutrition, and Weight Management, as well as its IT department, facilitated expanded partnerships including Shaw's Supermarkets, Boston Food Bank, Enterprise Rent-a-Car, and the Walmart Foundation.

Knowledge and Experience

SHARE staff are in agreement regarding the frequency with which they face the unexpected in serving their target population and the need for a structure and strategies suited to addressing issues that are unpredictable:

> *We're sort of like a light infantry. We can pick up and move... If there's something new that comes up we learn it, and adjust, and do it. (SHARE Administrative Staff)*

> *We argue a lot... Sometimes we go in one direction and we think things are okay, and we follow that direction and then something else comes up. I think every time you apply one thing a different set of circumstances can creep up, and having other people that are around that have vastly different experiences really helps. You're never going to catch every situation [in advance], so the best you can do sometimes is to react.....and the more [staff] diversity you have the better. (SHARE Case Manager)*

> *Nursing is normally a lot of black and white. In this job... there's a lot of grey. And, you've got to just keep digging and digging and digging. (SHARE RN)*

In addition, staff are in agreement regarding an unanticipated level of need. The lack of basic knowledge among clients regarding common illnesses such as cancer and diabetes, healthy behaviors, and independent living skills (e.g. grocery shopping, microwave operation) was surprising even to those with many years experience serving the homeless. One SHARE client received a diagnosis of cancer, following a routine Pap smear. She was not adherent to medical advice, because she did not understand certain basic facts: that treatment was necessary even in the absence of symptoms, that cancer can spread, and that it can be fatal. The staff found that this lesson, regarding starting with the most basic information, was important to communicate to their medical partners, who commonly had unrealistic expectations about SHARE clients' health literacy and health management skills, despite experience with homeless populations.

CHALLENGES

SHARE staff have identified a number of implementation challenges that likely would resonate with providers serving similar populations and/or utilizing similar models. Among these challenges:

- SHARE provides *intensive services* for people with few resources and limited access to entitlement programs. Although certain efficiencies are attainable, such programs face fundraising challenges, particularly in an environment that emphasizes cost savings and demonstrated potential for sustainability. Consistent efforts to access and diversify funding sources are required and must be considered "business as usual."

- The question of *appropriate threshold for service delivery resonates* throughout the SHARE program. The RN, for example, sees her role as time limited: *I don't want them to be dependent on me. That's what I always try to say. I'm like the ship. I'm going to steer you into port. Once we get into port and everybody's secure, I go on to the next person.* In fact, the SHARE program identified a significant minority of clients that had attained levels of self-sufficiency great enough for discharge from the program. However, some clients will never be "secure," and the need for intensive services may be ongoing.

In addition to the question of duration, there are questions regarding frequency and type of services. SHARE is targeted to very high need individuals, and services provided include those expected of traditional care coordination programs, such as health education and promotion, patient navigation, case management, and client advocacy. However, more basic services are also provided to some clients, including food shopping, food pantry pick-ups, and meal preparation. For the long-term homeless and those with cognitive difficulties, these basic service needs may also be ongoing. There are legitimate questions regarding the appropriate scope of services, given limited staff and program resources, as well as the goal (sometimes unrealistic) of increased client self-sufficiency.

A second perspective on scope and threshold for service delivery reflects the need to identify the appropriate level of care that keeps clients safe and able to maintain an optimal quality of life. A SHARE case manager wondered: *"If this person needs so much attention, could they be somewhere*

else? Or should they be somewhere else? ... If [it] means that a person is going to be in their home and suffering for X amount of time without any attention. I mean, we go home on weekends."

Evaluation of programs such as SHARE present numerous challenges. First, evaluation of person-centered services is inherently challenging as the "intervention," by design, differs according to the person. Outcomes (e.g. improved disease management, increased socialization) may also differ according to the person. Second, evaluation of services for frail older adults is challenging, given the declines in health and functioning that are an unavoidable part of the aging process. Improvements from baseline are not necessarily a realistic expectation. Third, SHARE is primarily focused on prevention of repeat homelessness. Without a control group and a robust study design, documenting that an event was prevented by a particular set of activities is near impossible. Fourth, given previous poor access, utilization of healthcare services is likely to increase for SHARE clients with program engagement. Thus, rather than reducing healthcare costs, SHARE may increase them. Similarly, common health status indicators might appear to worsen with the receipt of program services, due to recognition and treatment of previously undiagnosed health conditions, including diabetes and cancer. Fifth, commonly used measures of health status and health behaviors may be inappropriate for this population. For example, given extreme poverty, does "minutes walked per day" indicate healthful behavior or lack of funds to access needed transit services? Similarly, although regular consumption of fruits and vegetables is important—particularly given high diabetes rates—is it an appropriate expectation for individuals with limited access to food, in general? Sixth, given the volume and intensity of services provided, it is difficult for direct service staff to document all program activities and accurately report on frequency of client contact, as might be expected for a comprehensive process evaluation and/or cost study.

Despite these challenges, SHARE has continued to engage in a mixed method evaluation process, which has yielded useful data regarding the volume and type of services delivered and changes in client level outcomes.

SUMMARY AND LESSONS LEARNED

SHARE staff are devoted advocates for homeless older adults, working diligently to identify and implement a service model that best meets client needs. They are realistic with respect to client independence and skills, while

respecting both the moral obligation to care for those with limited ability to care for themselves and the resilience apparent in overcoming repeated obstacles. In describing their key lessons, recurrent themes include:

1. The significance of competing priorities, most notably food access and health issues as competing with housing needs, and the challenges to addressing these priorities. If food and health are not considered, housing is unlikely to remain stable.
2. Reflecting the competing priorities noted above, flexibility and creativity to provide services on an as-needed basis, even if that means multiple encounters per week—and providing services that do not fit typical case management or nursing expectations.
3. The necessity of starting at "step one"—the most basic information and/or services, as clients may have last visited a doctor's office or supermarket decades ago and may lack the confidence and trust for effective interactions. Use of a "housing first" or "harm reduction" approach facilitates the acceptance of person-centered, rather than universal, behavioral goals.
4. The importance of home visits, which allow the staff to observe and address what clients eat and drink, their independent living skills, medication access and practices, and other indicators of quality of life and stability.
5. The need for collaborators with complementary programs and services, including in-home medical care, food programs, and senior center services.
6. The importance of knowledge regarding entitlements and programs for particular populations, such as undocumented immigrants.
7. The need for diligence and concerted efforts to secure sufficient funding to meet a particularly high level of need.

In conclusion, SHARE offers a successful model to support aging in place and reduced homelessness for a particularly vulnerable population of older adults. The SHARE model involves frequent and flexible interactions that meet a wide range of basic needs and facilitate improvement in a number of intermediate outcomes, including mood, socialization, food security, and alcohol consumption. Given this range, it also requires collaboration, so that specialized services may be delivered in ways that are accessible and acceptable and serve the ultimate goals of housing stability and improved quality of life.

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