



Sharing Your Wishes™

Give Them Peace of Mind, Not Tough Choices.

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**Program Summary Report
2004-2008**

Sharing Your Wishes™: Community Coalitions Improving Health Care Decision- Making through Advance Care Planning

Part A: Background

Introduction

In 2004, the Community Health Foundation of Western and Central New York (the “Foundation”) launched a project to identify and subsequently support community coalitions in facilitating improved health care decision-making. The objective of this project was:

To strengthen the capacity of selected community coalitions in order to improve the quality of care and quality of life for the most frail elders through increasing public awareness and stimulating practice and system changes in health care decision-making

The Foundation Board was particularly interested in focusing on:

- Patient-centered care in which the well informed preferences of the individual come first and are honored by their families and providers;
- Appropriate medical care that adheres to the highest quality standards;
- Palliative care, which is care designed for mitigation of pain and suffering;
- Coordinated approaches to care as practiced by physicians, nurses and institutional health care providers; and
- The roles of committed families and communities in achieving the goals related to improvements in quality of care and quality of life.

Project Rationale

In 1900, life expectancy at birth for a white female was 47.3 years. In 2000, some estimates are that a 50-year-old white woman’s life expectancy was 93 years. In other words, the United States has experienced a doubling of life expectancy in one century. In 1940, there were only about 300,000 Americans over 85, while it’s projected that in 2040, over 18 million Americans will exceed that age. The U.S. health care system is unprepared for the care needs of a larger and increasingly frail cohort over 85. Unfortunately, as we age, so does the length of time we are likely to be ill and disabled, thus leading to an increase in the number of medical interventions that individuals are likely to receive. Diseases such as congestive heart failure, chronic obstructive pulmonary disease, cancer, stroke, and Alzheimer’s Disease all contribute to a prolonged period of disability and illness before death.

And yet, it is in these late stages of life – when we have the most contact with the health care system – that the voice of the individual is often drowned out by a system that takes over and manages the conditions, not the human being. This is done not because of malicious intent, but because of the sheer momentum of a system designed to diagnose and cure, rather than accommodating long periods of chronic illness, meeting the needs of very frail elderly patients, or addressing the diverse needs of dying patients.¹

It is during these latter years of frailty that we see the impact of such a system:

- People’s decisions and preferences about how they want to live their last years may not have been articulated or well thought-out. If not shared and reinforced, these preferences are often not honored by the providers who treat them, especially when the person cannot speak for him or herself.
- Over-treatment occurs frequently, especially where a particular condition or acute symptom is treated in isolation from the person’s overall physical and mental condition.
- Pain and discomfort is poorly managed, while frail elders suffer unnecessarily.
- Poor communication among the numerous agencies and providers in the flow of care delivery results in less than optimal care – and can even exacerbate health issues.
- Families feel frustrated, conflicted and unsupported in their attempts to do the right thing for their loved one.

The Institute of Medicine, Agency for Health Care Research and Quality, The Robert Wood Johnson Foundation, and many other organizations have developed various strategies to address this continuing tragedy. All of that work points to the need for “a whole-community approach...that includes a mix of programs, settings, personnel, procedures and practices that extend beyond health care institutions and policies.”² The overall goal of such a whole-community effort is to establish accountability for high quality care throughout life, particularly for the frailest community members.

Why Community Coalitions?

It has often been said that health care is a local issue – it’s locally provided and locally consumed. That means that with the exception of changes that can be implemented through major policy revisions, people and care systems need to be impacted where they are and in unique ways that work for each community. For this reason the Foundation chose to engage local coalitions as partners for this effort.

Local coalitions have become recognized as effective structures for fostering innovation and improving community-wide health outcomes.³ Coalitions, defined as “inter-organizational, cooperative, and synergistic working alliances,”⁴ have the capacity to involve diverse

¹ Lynn, Joanne, Schuster and Kabcenell, Improving Care for the End of Life, Oxford Press, 2000., p. 3-4

²Institute of Medicine, 1997

³ Roussos, S.T. & Fawcett, S.B. (2000). A review of collaborative partnerships as a strategy for improving community health. *Annual Review of Public Health*, 21, 369-402).

⁴ Butterfoss, F.D. (1993). Community coalitions for prevention and health promotion. *Health Education Research*, 8(3), 315-330.

organizations in addressing shared concerns. They allow stakeholders to come together in organized ways to enact multiple strategies aimed at building community capacity and changing individuals.

While coalitions offer ideal structures for supporting change in local communities, they have some disadvantages. Coalitions operate in the context of prior history, established social networks, and attitudes that are not always supportive of change.⁵ Coalitions are often unwieldy and unpredictable; they also depend on the participation of individuals who are skilled in group process, delegation, political skills, and working across interdisciplinary boundaries.

Given these challenges, the Foundation provided training and technical assistance regarding the nature of coalitions at the beginning of the Sharing Your Wishes project. An expert in community coalitions, Don Tobias, PhD, from Cornell University, presented a workshop entitled “Using Coalitions to Stimulate Community Change.” Tobias reviewed lessons learned from communities with successful collaboration efforts. He stated that effective collaboration includes five important factors: mutual benefit, individual vs. organizational identity, information exchange, trust, and resources. The workshop also stressed the following points:

- Coalitions are most successful when they step back periodically, allowing members to recommit to goals.
- Roles and membership of the coalition will change over time as the priorities change and the coalition evolves.
- A coalition includes representatives of organizations; over time the coalition increases its ability to provide accountability to the organizations being represented.
- A coalition is able to engage community leaders more effectively than a single organization.
- Long-term success of the coalition is strengthened by early successes.
- Through education and planning, the coalition can implement actions.
- Keeping track of the progress allows communication of the successful effort and will draw more resources, attention and involvement for future efforts.
- The ultimate goal is to engage the critical mass and to make the issues part of the public agenda.

⁵ Feinburg, M.E., Riggs, N.R., Greenburg, M.T. (2005). A network analysis of leaders in community prevention. *Journal of Primary Prevention*, 26, 279-298.

Part B: Program Design

Components of Three-Year Project

In 2004, the Foundation launched this effort with a pre-funding workshop highlighting the successful Gunderson-Lutheran Respecting Choices® program and ideas for successful change through community coalitions. The Request for Proposals was distributed to participants and, after a competitive selection, six counties were selected to participate in the first “learning community” project. Because of the emphasis on community outreach and education, the project started with the premise that grantees had to demonstrate that they were a pre-existing coalition with a focus on issues that related to older adults and Advance Care Planning (ACP). The six counties involved are Allegany, Cayuga, Erie, Genesee, Niagara, and Tompkins. In 2007, Onondaga County was added to the project.

Over the next three years, representatives of the six counties participated in workshops to learn about approaches to advance care planning, facilitator training, and presentation skills. They also participated in discussions about stimulating family conversations when dementia was a factor and when family dynamics were difficult. In addition, the group participated in discussions about system change efforts including staff development, working with primary care physician offices, and development of advanced care planning registries accessible via the Internet. In between the workshop sessions, coalition representatives met to share experiences, results, and ideas for next steps of project development. The coalition involvement was active and at times lively, and led to sharing among counties both in the group sessions and between learning events.

Year	Program Activities
2004	Program conceptualized
2004	Pre-Conference Workshop and Request for Proposals distributed
2004	Pre-funding orientation workshop (coalition-building/advanced care planning)
2005	Six coalitions funded (Allegany, Cayuga, Erie, Genesee, Niagara, and Tompkins)
2005- 2007	Coalitions met several times a year for workshops, discussion and sharing of experiences, results and program ideas
2007	Seventh coalition funded (Onondaga)
2007	Sustainability workshop/ coalitions developed sustainability plans
2007	First license agreement between a SYW coalition and Assuring Your Wishes (Internet registry)
2008	Sharing Your Wishes web-based tool-kit introduced
2008	Request for proposals distributed to fund additional coalitions

Figure 1: Timeline of Major Program Events

Over the course of the project, coalition representatives met together to problem solve, share experiences, and help each other strengthen their approaches. Working together and with the support of the Foundation, the project was named Sharing Your Wishes, (SYW) and materials were developed to support the project including:

- A planning guide to provide a simple, direct process to encourage conversations, selection of a health care agent and completion of a health care proxy form to give this person authority to speak for the individual if they become unable to communicate for his or herself,
- A booklet to provide additional information for people who want to explore in greater detail how to develop advance directives, how to think about health wishes, and how to understand health choices,
- A note card for individuals to give to their health care agents to help the agents understand their responsibilities,
- Posters to help spread the word,
- A DVD with video clips of key messages, case scenarios, and
- A media support guide (provided in the resource tool kit).

Every coalition attempted to measure the impact of each group's efforts. Given the structure of the coalitions and the self-management aspects of this effort, measurement was difficult. However, anecdotal responses from training participants, facilitators and local health care providers were readily available. Some of the measures used are included in the tool kit. The Foundation also gathered county-wide data from the participating counties as well as the other counties in the Foundation service area to track changes in practice indicators as identified by a small group of geriatric physicians.

The Foundation provided on-going support with advice and counsel as well as the resources necessary to develop the materials and a website for Sharing Your Wishes. Each county received an annual grant to cover development costs and at least partially cover some dedicated staff support. In the third year, a value-added component emerged from collaboration with an Internet registry for advance directives. This registry is named AssuringYourWishes.org, and was developed and endorsed by the Hospice and Palliative Care Association of NYS.

Several existing programs that supported health decisions and advance care planning were reviewed and considered for implementation by the coalitions. It was determined that components and messages from many of these programs could be used, but the coalition project needed to determine its own priorities and message. The main structure of the project was modeled after the Respecting Choices program developed by Gunderson Lutheran in La Crosse, Wisconsin. [<http://www.gundluth.org/eolprograms>]

The Sharing Your Wishes project began with an emphasis on **community engagement**, defined as “a process of creating and communicating a clear message to the public through education, publications and materials.” The emphasis was on helping individuals understand the importance of 1) planning ahead for their health needs, 2) understanding the choices that may be ahead, 3) identifying someone who could speak for them if they become unable to speak for themselves, and then 4) executing a health care proxy so the agent has the authority to make decisions.

Once community engagement was underway, all of the coalitions began to think about **professional education** and **systems change**. This emphasis was based on their recognition that sustainability for an innovation like advance care planning requires a culture change by health professional and organizations. In professional education venues, the coalitions worked with community agencies to adapt orientation and continuing education approaches, and to train facilitators within health care provider agencies.

They also pursued **systems change** in their communities by working to implement changes in policies and procedures within health care organizations. These changes were aimed at approaching the requirements for asking about advance directives in a different way. The idea to create an Internet registry to make sure that advance directive documents are accessible grew from the system change aspect for sustainability. As the SYW coalitions were exploring options to develop an Internet registry, they were informed about a similar effort being started by the Hospice and Palliative Care Association of NYS through Hospice of Rockland County and collectively made the decision to work together on this rather than create a registry for Sharing Your Wishes counties. As part of this cooperative effort, the Foundation supported the coalitions with the development of www.sharingyourwishes.org.

Part C: Coalition Case Studies

Allegany County Coalition

Context

Allegany County is a rural county located along the Southern Tier in Western New York. The rural setting impedes the delivery of health care and other services. Allegany County is the poorest county in New York State based on per capita personal income. One out of every six county residents receives Medicaid. Approximately one out of seven residents is over 65 years of age. These factors lead to significant challenges for consumers as well as for the health care and service delivery systems of the county including, but not limited to, access and transportation.

Coalition Description

In 2005, the Allegany Senior Foundation received funding, on behalf of the County Community Partnership on Aging coalition, to implement the Sharing Your Wishes project. The SYW Advisory Committee was formed and included representatives from local hospitals, skilled nursing facilities, Home Care and Hospice, faith-based organizations, Department of Social Services, Office for the Aging, and the Allegany Senior Foundation. This committee met monthly to address and carry out the goals and objectives of the project and monitor outcomes. In addition, this committee was responsible for developing and implementing program activities, providing community links to resources, marketing the program to the greater community, and conducting long-term strategic planning for ongoing sustainability.

Organizational Structure

The coordinating organization for this initiative was the Allegany/Western Steuben Rural Health Network (AWSRHN), founded in 1994 as one of 35 RHNs in New York State. The network's mission is to improve the health and wellness of our community by collaboratively identifying unmet needs and gaps in services, and serving as a catalyst for program development and improvement. The AWSRHN hired a full-time SYW Coordinator who convened, organized and mobilized the partnership and other members of the community to share the responsibility of improving systems and engage the community around advance care planning (ACP).

Community Engagement

Community Engagement was key to the success and sustainability of the goals of the SYW initiative. Utilizing a social marketing model, many important steps were taken to engage the different sectors of the community. Surveys and focus groups were conducted to identify the cultural environment around ACP. Also, organizational capacity was assessed in order to determine professional education needs, current practices, and policies and procedures focused on ACP. The assessment measured the readiness of frail elders and helped the coalition understand and learn from the community what strategies would work best. Four segments of the population were identified as important to reach frail elders: Medical Professionals, Faith-Based Organizations, Legal Professionals, and Informal Caregivers.

Professional and Community-based Education

The assessment process guided the plans for professional and community-based education and outreach activities. In 2006, a two-day Respecting Choices® Facilitator Train-the-Trainer workshop was conducted to help increase the number of health care providers active in promoting successful advance care planning. As a result, Facilitators worked one-on-one with community members and/or implemented internal employee education programs in their organizations.

The Coordinator offered support to medical providers through office staff training and in-service training, as well as consumer-based educational materials onsite.

Three different strategies were used to increase faith-based leader's knowledge and understanding of ACP. In 2006, a one-day SYW workshop provided faith-based leaders and legal professionals with the tools necessary to assist their constituents. In addition, faith-based leaders were invited to attend a six-week series of educational forums around end-of-life issues. This was based on the National Hospice Foundation of America model. In 2007, faith-based leaders were invited to attend a one-day conference that was developed in response to the feedback received from previous sessions.

The SYW Coordinator provided a variety of educational programs to health and human service agencies and community groups and participated at numerous community health fairs, staff in-service trainings, service organizations, local universities, and support groups.

Throughout the project, the coalition distributed educational materials provided by the Community Health Foundation to individuals as well as area health care agencies and organizations. Working with Allegany County Emergency Medical Services captains, the SYW Coordinator developed and produced a standardized health file for use by frail elders and others to store important health care documents. The Health Files contain documents such as Advance Directives, Medical History Form, Universal Medical Sheet and non-hospital Do Not Resuscitate (DNR) forms. Processes were put into place so that caseworkers going into the home would update the information as deemed necessary.

To assist informal caregivers through the process of advance care planning, the SYW Coordinator and volunteer facilitators provided one-on-one family-based assistance to complete advance directives.

Systems Change

One of the overall goals of the SYW program was to create system change that would facilitate standardization and more efficient and effective procedures for advance care planning.

- Sharing Your Wishes sponsored an educational program by Dr. Patricia Bomba, of Excellus, to improve the transition of shared information among long-term care facilities and hospitals. As a result of this training, improved admission procedures between the institutions have been implemented to ease the transition of medical records, including advance care directives from one provider to the other.
- Sharing Your Wishes has also been incorporated into the NY Connects – Allegany Connects, single point-of-entry procedures.
- Health Files improved health information from the community to the medical providers. This empowerment tool encouraged individuals to take a more proactive role in tracking and sharing their healthcare information.

Medical providers have instituted quality assurance tracking to monitor the success of changes in advance care planning process.

Summary

Sharing Your Wishes funding helped enable Allegany County providers to proactively embrace advance care planning. SYW has enabled us to address the social, financial, psychological, physical, and spiritual needs and wishes of frail elders, caregivers, and the health care delivery system. This initiative struck a personal note in everybody that was involved, and evoked passion from a broad constituency of representatives of the community.

At the conclusion of the three-year grant cycle many factors have led to the overall success of this local project. The support of not only the CHFWCNY, but the collective work accomplished by all the coalitions, provided a forum to successfully address the challenges faced along the journey and to profit from one another's experiences.

Cayuga County Coalition

Context

Cayuga County is a small, rural county in central New York with a population of 81,963 at the time of Census 2000. Over eighteen percent of the population (15,044) is above 60 years of age, a percentage that is above the state average. The 85-and-over segment is growing the fastest – it increased by more than twenty-six percent between 1990 and 2000. Project 2015, a report by the NYS Office for the Aging, predicts a forty-eight percent increase in Cayuga County's 85-and-over segment by 2015. The long-term care system in Cayuga County includes one hospital, five nursing homes, one assisted living facility, and six adult homes.

Coalition Description

The Elderly/Disabled Task Group of the Human Services Coalition of Cayuga County received funding to implement the Sharing Your Wishes project. The Task Group is made up of approximately thirty members who represent providers of services to the elderly, disabled, and general consumers. This task group has been in existence since 1996 when it began by identifying the major needs and gaps related to care of older adults in Cayuga County. The lead organization for the project was United Way of Cayuga County. The Human Services Coalition of Cayuga County, which is a partner agency of United Way, coordinated and managed the project.

Key organizations included members of the Elderly/Disabled Task Group and other stakeholders in the long term care system in Cayuga County, including staff from the Auburn Memorial Hospital, Hospice of the Finger Lakes, adult homes, assisted living and nursing homes, Cayuga County Home Care Agency, and the Long Term Care Access Office, Office for Aging, and Caregiver Support Program.

Organizational Structure

The coalition implemented their program through the efforts of a half-time project coordinator for the first year and a part-time (30%) project coordinator during year 2 and 3. In addition to staffing, the Human Services Coalition provided the administrative support for the project by conducting regular meetings over the course of the project, organizing activities, financial management, and reporting on programming. A SYW Oversight Committee was convened to oversee the work of the project and to report to the Elderly and Disabled Task Group.

Community Engagement

The project initially conducted a community-wide assessment process that indicated that ACP efforts must be completed by individuals and their families prior to placement in a nursing home. Based on this assessment, the Coalition augmented its original plan, which focused heavily on increasing the number of residents in nursing homes and adult homes with ACP, to include well seniors, facility employees, middle-aged, county employees, etc.

Throughout the project, the coalition distributed educational materials from the Community Health Foundation to individuals as well as area health care agencies, churches, physicians, and other organizations. They employed creative way of distributing these resources, including the distribution of Sharing Your Wishes materials in the form of placemats at congregate meal sites for older people and through distribution in health files. Materials were spread through the Red Cross Newsletter, the Red Cross Office, Catholic Charities, local HEAP site, Meals on Wheels,

Health Department, local doctor offices, EPIC Family Resource Center, Senior News and Views Newsletter and many other local sites.

Professional and Community-based Education

The Cayuga County Coalition provided training in their community to health care personnel, human services staff, volunteers, caregivers and individuals on ACP. These efforts were conducted in the form of 1) in-service workshops for nursing and adult homes and clinics; 2) SYW presentations to community groups; and 3) collaborative presentations with Long Term Care Insurance program. The coalition also incorporated contests, food, and entertainment into these events to increase the participation in educational programs and the number of completed HCPs. A partial list of programs that were presented includes these events:

- Auburn Prison Employee Awareness Day
- Senior Citizen Day, Emerson Park
- Cayuga County Department Head Meeting
- Medically Speaking Series, Auburn Memorial Hospital
- Cayuga County Council of Senior Citizens
- Heart Expo, Auburn Memorial Hospital
- Community Service Fair, Auburn Chamber of Commerce
- Our Mothers, Our Daughters, Our Health
- Nurse's Night Out sponsored by the Asthma Coalition
- Senior Law Days

Systems Change

This coalition built on the strength of the Human Services Coalition of Cayuga County and used it as a great asset to accomplish their goals. One hallmark of their operating process was the incorporation of their work into that of other community-based organizations. For example, SYW project updates were provided at Coordinating Council Meetings, Elderly and Disabled Task Group Meetings, and to the project's Oversight Committee on a monthly basis. This network of agencies provided an ongoing source of information, presentation possibilities, and support for the project. Materials and resources were distributed to the 90 Human Services Coalition agencies and they each made them available to staff and clients.

The coalition facilitated local access to a central registry for advance directives through the AssuringYourWishes.org registry. The coalition established a relationship with Hospice of CNY to administer the registry for the county.

Summary

The coalition began with a strong project coordinator who was able to set many components in place during the first year. The project was able to collaborate with a quality improvement project team focused on improving transitions to develop a successful health file effort. As the project continued with reduced staff support, the emphasis shifted to adapting efforts from the other coalitions including cooperative efforts with Tompkins County Coalition in the development of the staff development tool kit and work with Niagara to adopt their complementary Never Too Old program to ensure the sustainability of the Sharing Your Wishes effort.

Erie County Coalition

Context

The county is located in a major (Buffalo-Cheektowaga) metropolitan area. According to the U.S. Census Bureau, the estimated population in 2004 was 936,318. This was a decrease of 1.5% from the 2000 census. At the same time, Erie County's aging population is growing and Erie County ranks 16th out of 236 counties nationwide for the size of its older population. Erie County has a total area of 1,227 square miles, and is the most populous county in New York State outside of the New York City metropolitan area. The county is located in the western portion of New York State, bordering on the lake of the same name. Due to its metropolitan nature, Erie County has a multitude of health and human service organizations, including several major medical centers and hospitals.

Coalition

The Western New York Health Care Proxy Coalition received funding for the Sharing Your Wishes project in 2004. As part of this work, the coalition changed its name to the Coalition for Health Care Decision Making. The lead organization was the Center for Hospice & Palliative Care. This organization was designated to provide a staff coordinator, meeting space, and in-kind project support with mailings, website renewal/coordination, and sponsorship of coalition activities.

Organizational Structure

Staff support for coalition activities were provided in the form of a Coalition facilitator 6 hours/week and a part-time (10 hours per week) project coordinator at St. John Baptist Church. Participating organizations included Assemblyman Robin Schimminger's Office, BlueCross BlueShield of WNY, the Catholic Health System, The Center for Hospice & Palliative Care, Erie County Department of Senior Services, Erie County Department of Health, Independent Health, Kaleida Health, Medical Society of the County of Erie, University at Buffalo School of Nursing, Upstate New York Transplant Services, and Univera Healthcare.

Community Engagement

The coalition engaged the community in project activities using many different methods to reach a wide variety of audiences. One major project activity was the development of a trained professional and volunteer network with the capacity to provide ongoing training in advanced care planning. Over the course of the project, they provided Respecting Choices® Facilitator Train-the-Trainer workshops which resulted in 98 trained Advance Care Planning Facilitators, exceeding the original goal of 80 trained facilitators. These trainers and facilitators will provide a network of trained, committed volunteers who can sustain educational activities related to advanced care planning beyond the grant period.

Intensive educational activities were focused on a local spiritual organization, St. John Baptist Church, to train clergy, facilitators, an advanced care planning team, and other members to provide advanced care planning to parishioners. The coalition also incorporated contests, food, and entertainment, conducted educational programs, and distributed educational resources to a wide variety of organizations. A partial list of programs that were presented includes these events:

- Sharing Your Wishes presentation to Moot Senior Center and St. John Baptist Tower for senior-housing
- Sharing Your Wishes 1:1 ACP sessions with seniors in community
- Sharing Your Wishes article published in the Criterion, a black community newspaper
- Sharing Your Wishes public affairs radio programs
- Sharing Your Wishes cable television interviews
- Advance care Planning presentation to Baptist Ministers Conference

Professional and Community-based Education

The coalition made it a priority goal to create a relationship with two active medical practices and developed a working model for discussing advance care planning in a comfortable and supportive way with patients, thus increasing the number of patients who have completed their advance care directives. In order to accomplish this goal, coalition staff trained mid-level professionals (nurses, nurse practitioners, physician assistant and others) in the practice to continue the conversation launched by the physician (targeting chronically ill patients over the age of 65). This protocol was launched at the Community Health Center of Buffalo, Inc., which is an urban clinic serving approximately 7,000, primarily African-American patients a year. In Year 3, the Coalition established ACP sessions for patients utilizing three trained facilitators at Buffalo Medical Group, the largest physician practice group in Western NY.

Systems Change

The coalition placed an emphasis on building capacity for advance care planning efforts within their community, working within two large health care provider practices.

Community Health Clinic of Buffalo outcome:

Prior to intervention 0% of patients had health care proxy (HCP) in their chart	Post-intervention 30% of patients had HCP in their chart
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Buffalo Medical Group outcome:

Prior to intervention 21% of patients had HCP in their chart	Post-intervention 79% had HCP in their chart, an increase of 58%.
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One major outcome of the project is that they facilitated local access to a central registry for advance directives in the form of the Assuring Your Wishes registry. The Center for Hospice & Palliative Care is the local sponsor for this registry.

Summary

Over the course of the project, this coalition used many different methods to reach their goals. They leveraged the resources of the organizations within their coalition to reach diverse audiences and expedite educational activities and resource distribution. They maintained the size of their large, diverse coalition. They provided education in the form of workshops and presentations to a wide variety of local organizations, including health care, human services, clergy, caregivers, payor organizations, and consumers, which increased the level of awareness of participants to many issues associated with advanced care planning.

Genesee County Coalition

Context

Genesee County is a rural county located in Western New York. As of the 2000 census, the population was 60,370. Its county seat is Batavia, a small town with a diverse economic base including agriculture and tourism. In 2000, the median income for a household in the county was \$40,542. Males had a median income of \$34,430 versus \$23,788 for females. The per capita income for the county was \$18,498. About 5.6% of families and 7.6% of the population were below the poverty line, including 9.0% of those under age 18 and 6.8% of those 65 or over.

Coalition

The Long Term Care Task Force, which was originally convened in June 2003, received funding in 2005 for the Sharing Your Wishes project. The key organizations for implementing the initiative were the local medical society and local hospital administration, the faith-based community, hospice, terminal comfort care programs, physicians & their office staff, long term care provider agencies who choose to participate (such as the Visiting Nurses Association), the health department's Certified Home Health Program, Hospice and Homecare, and area nursing care facilities. Other involved groups included older people and their caregivers - advocacy groups, local media, and service organizations. Over the course of the grant period, other organizations were recruited for involvement in the coalition, including representatives from 15 churches, 25 long-term care/health care professionals, 5 physicians and a paralegal.

Organizational Structure

The Genesee County Office for the Aging (GCOFA) was the lead agency in applying for this grant. As the lead organization, GCOFA housed an Aging Services Specialist who acted as a part-time (19 hrs. per week) coordinator for the project. GCOFA involvement also included conducting the LTC Task Force meetings and placing this initiative on the agenda for the full GCOFA meetings. GCOFA was integrally involved in all aspects of the grant activities from both a supervisory and programmatic role.

The coalition established 3 active sub-committees to plan and implement grant activities: Heightened Awareness, Facilitation and Systems Change. They met at least every other month. Copies of sub-committee rosters, meeting agendas and minutes were placed on file at the Office for the Aging.

Community Engagement

The coalition adopted the Gunderson Lutheran Facilitator Training program, and over the course of the funding period, trained 217 facilitators which includes BOCES and Genesee Community College Nursing Students. These facilitators targeted their efforts on individuals in health care system or agencies that work closely with older adults, such as caseworkers, nurses, social workers, discharge planners, etc.

Professional Education

Over the course of the project, the coalition presented a variety of educational programs to many organizations and agencies throughout the county. They strengthened their existing training resources, with an emphasis on Genesee Community College's inclusion of Advanced Care Planning Facilitation into their required *Lifespan* curriculum for RN students, and also strengthened their facilitation of relationships with BOCES LPN students. In addition, they

facilitated presentations to human services point-of-entry staff, faith-based volunteers, legal service providers, and physicians' offices.

Systems Change

Systems change efforts included an examination of the current system for ACP and how advanced directives are (or are not) carried out. The coalition explored real world issues including obstacles to good advanced care planning and devised several system that were responsive and realistic to implement. These included efforts to work with first responders to distribute readily accessible "Health Files" (see description below). This process was aimed at improving the advanced care planning process for frail elders and their family members, as well as the medical community.

The coalition worked with CHFWCNY to implement a central registry (Assuring Your Wishes) for advance directives, which will coordinate with the local healthcare network, and will also include accessibility via the Internet for-out-of-the-area providers. They facilitated an agreement with United Memorial Medical Center to be the local sponsor of the Assuring Your Wishes registry.

Summary

The Genesee County coalition was successful in their efforts to build awareness regarding ACP in their community. They leveraged several unique strengths to accomplish their goals. One notable aspect of the coalition was their longevity as a working coalition. Another characteristic that influenced their success was the unusually long tenure of many coalition participants acting in leadership roles. These factors provided the coalition with a foundation comprised of strong institutional ties, long-term working relationships, and thorough knowledge of community systems. Finally, their committee structure helped to keep coalition members actively involved and allowed them to succeed in several areas.

Niagara County Coalition

Context

Niagara County is located in the extreme western part of New York State, just north of Buffalo and adjacent to Lake Ontario on its northern border and the Niagara River and Canada on its western border. As of the census of 2000, there were 219,846 people, 87,846 households, and 58,593 families residing in the county. The population density was 420 people per square mile. The demographics of Niagara County's population are diverse, with 24.70% under the age of 18, 8.50% from 18 to 24, 28.40% from 25 to 44, 23.10% from 45 to 64, and 15.40% who were 65 years of age or older. The median age was 38 years.

The median income for a household in the county was \$38,136, and the median income for a family was \$47,817. The per capita income for the county was \$19,219. About 8.20% of families and 10.60% of the population were below the poverty line, including 15.00% of those under age 18 and 7.30% of those 65 or over.

Coalition

The Niagara County Sharing Your Wishes project was conducted by the Niagara Caregivers Network (NCN), a consortium of medical, emotional and spiritual care organizations in Erie and Niagara counties (although the project only focused on Niagara County.) The mission of the NCN is to improve the quality of life of older adults and their caregivers through education, training and other collaborations that encourage referrals to existing community resources. The coalition included representation from the Niagara County Health Department, the Niagara County Office of the Aging, the Erie County Department of Senior Services, Catholic Charities of Western New York, the Center of Renewal at Stella Niagara, the Lewiston-Youngstown Clergy Association, the Network on Aging, the Mental Health Association in Niagara County, the WNY Parish Nurse Institute, AARP and Health Association of Niagara County (HANCI)

Organizational Structure

The NCN's SYW project was administered by the Council on Aging of Niagara County, Inc., which was incorporated as a non-profit, non-sectarian and non-political organization on August 2, 1972. The program was staffed by a half-time coordinator, who was guided by the Niagara Caregivers Network Board as well as the Board and staff of the Council on Aging.

Community Engagement

The coalition launched a train-the-trainer effort aimed at educating local organizations to integrate ACP materials into their practices. They engaged numerous organizations in the distribution of educational materials. The following is a selected list of these efforts.

- AARP conducted a 10,000 piece mailing
- The Dale Association, Niagara Hospice and the Department of Aging agreed to serve as ongoing sites where people picked-up SYW materials
- SYW was promoted on local cable television shows and newspaper articles

The Council on Aging, made up of representatives from more than 40 senior clubs and centers across Niagara County focused on Sharing Your Wishes at its Spring, 2006 conference. In addition, Sharing Your Wishes workshops have been offered at the COA's 2007 and 2008 annual conferences.

Professional Education

The coalition worked through many Niagara county organizations to leverage their involvement in SYW education targeting local professionals. An example was their work with the Niagara Coalition of Agencies in Service to the Elderly (CASE), which dedicated its spring 2006 conference to Sharing Your Wishes. In this conference, eldercare professionals from over 50 organizations were trained to initiate SWY programs within their worksites, and to take steps toward integrating SYW into their organization's policies and procedures.

Niagara Hospice adopted SYW as part of its program for end of life care, resulting in 150 relevant staff and volunteers who received training. In addition, the Niagara County Health Department Home Health Services were trained in SYW and now include SYW whenever they open a new case. Similarly, the HANCI home health nurses have been trained to use SYW when they open new cases.

Systems Change

The Niagara County Office of Aging collaborated with the coalition to include SYW as an important component of their "Never Too Old" point of entry program – a "whole person" program, which also aims to enhance patient-centered decision making among seniors, the frail elderly, and their caregivers. This integration was accomplished in the form of 1) wallet cards with ACP information printed on them, and, 2) a "Sharing Your Wishes" video. Both of these resources were developed, implemented, and evaluated by the coalition. The "Sharing Your Wishes" video, tells the story of a woman whose mother died from Alzheimer's Disease, was developed for use in both professional and community education.

Everyone who contacts NY Connects - Niagara County Point of Entry operated by the Niagara County Office for the Aging and Department of Social Services, will be asked whether or not they have completed a NYS health care proxy form. This data will be tracked and reported as part of the Office for the Aging's annual Satisfaction and Needs Survey. If they have not, they will receive "Sharing Your Wishes" video and materials included in the "Never Too Old" which is also available on the website: www.NeverTooOld.net/niagara.htmT.

The coalition worked with community partners to implement access to the Assuring Your Wishes central registry for advance directives through an agreement the Council on Aging, which will serve as the local sponsor of the Assuring Your Wishes registry.

Summary

The Niagara Coalition accomplished their original goals of 1) involving frail seniors, their caregivers and the organizations that serve them, and 2) integrating advanced care planning into the locally established "Never Too Old" training curriculum. They accomplished these goals by building on their established ties to local organizations and health and human services professionals. They successfully introduced "Sharing Your Wishes" resources into their community, while at the same time developing additional tools to further extend ACP education in new and creative ways.

Onondaga County Coalition

Context

Onondaga County is an urban county located in the central New York region. As of the 2000 US census, the population was 458,336. It has a land area of 793.5 square miles and is approximately 35 miles in length and 30 miles in width. Onondaga Lake is a major geographical feature and is bordered by many of the larger communities in the county. The City of Syracuse is situated in the approximate center of the County and serves as the focus for commercial and business activities. According to the 2000 U. S. census, the Syracuse population was 147,306.

Coalition

Unlike the other Sharing Your Wishes coalitions which were funded in 2005, the Onondaga coalition was funded in 2007. The Onondaga Community Coalition was made up of 10 organizations, including the Alzheimer's Association of Central New York, Crouse Hospital, Hospice of Central New York, Institute for Ethics in Health Care, Long Term Care Executive Council, St. Joseph's Hospital, Transitional Living Services, Upstate Medical University, InterReligious Council of Central New York, and Loretto. Efforts have been made to broaden the diversity of the coalition by recruiting additional organizations.

Organizational Structure

The Institute for Ethics in Health Care (IEHC) administrated the grant, which provided a portion of staff support for the IEHC executive director. A part-time program coordinator began in October 2007 with funding one day per week from the Allyn Foundation. The coalition relies extensively on the leadership and commitment of community volunteers and in-kind support from various agencies.

Community Engagement

The coalition invested its grant dollars to provide "Respecting Choices" facilitator training by Gunderson Lutheran Hospital of La Crosse, Wisconsin. This program framed the comprehensive "advance care planning" for 2007. Approximately 32 facilitators were trained on October 2, 2007; this training was followed by a subsequent training on October 4, 2007, when seven Facilitators participated in the Facilitator Instructor Course and were certified as Instructors.

Professional Education

The coalition facilitators met on a monthly basis since the October training to prepare for presentations to local organizations and health providers. They utilized resources that were developed by the other coalitions. For instance, the group adapted a PowerPoint presentation developed by the Cayuga County SYW. Many of the facilitators used their Advance Care Planning skills in both group presentations and individual counseling settings. A selected list of presentations to community groups includes:

- Human Services Leadership Council
- Transitional Living Services (TLS)
- Syracuse East District Episcopal Church
- St. Joseph's Hospital
- University Hospital's Continuum of Care Department
- University Hospital's Office of Training and Development
- Onondaga County Nurses Association

- Palliative Care Course--Presentation to 3rd Year Medical Students and Chaplains

Systems Change

The coalition participated in planning and implementation of access to a central registry for advanced care planning for residents of Onondaga County. This resulted in an agreement between Assuring Your Wishes and the Hospice of Central New York.

Resources in the Tool Kit

Due to the recency of funding, the coalition did not develop any original products. They modified many existing products related to advanced care planning to make them applicable to local needs.

Summary

The Onondaga SYW coalition is relatively young. However, they were successful in building an infrastructure of community organizations to actively support project activities. They have trained facilitators and facilitator instructors, who in turn will participate in project presentations and training activities. This focus on building organizational and individual capacity is expected to provide the foundation for program sustainability over the coming years.

Tompkins County Coalition

Context

Tompkins County is a semi-rural county located in the Finger Lakes region of central New York. It comprises the whole of the Ithaca metropolitan area. The county is home to Cornell University and Ithaca College. As of the census of 2000, there were 96,501 people, 36,420 households, and 19,120 families residing in the county. The population density was 203 people per square mile. The population is 19% under the age of 18, 26% from 18 to 24, 26% from 25 to 44, 19% from 45 to 64, and 10% 65 years of age or older. The median age was 29 years. The median income for a household in the county was \$37,272, and the median income for a family was \$53,041.

Coalition

The Tompkins County Long Term Care Committee (LTCC) was funded to administer the Sharing Your Wishes project in Tompkins County. The committee is a standing committee of the Health Planning Council (HPC), which in turn is a program of the Tompkins County Human Services Coalition (HSC). The HSC is a private non-profit organization focusing on efficient, effective planning and delivery of human service programs; the HPC concentrates on improving the health care system to enhance the health status of Tompkins County residents.

Organizational members of the coalition included Cayuga Medical Center at Ithaca, County Office for the Aging, Family & Children's Services Home Health Care program, Finger Lakes Independence Center, Hospicare and Palliative Care Services, Ithaca College Gerontology Institute, Lifelong, and Long Term Care Services.

Organizational Structure

The Tompkins initiative was directed by a 25% Coordinator (provided in-kind) and a 35% Program Assistant (supported by the grant). The Coordinator managed the project and conducted major parts of the work. The Coordinator had responsibility for planning, developing and coordinating the initiative in all its phases and was the primary spokesperson. She oversaw all phases of the operations and was responsible for project performance and the observance of all budget and personnel policies and procedures. She worked with the LTCC to carry out the activities and was responsible for writing and analyzing reports. The Program Assistant worked under the direction of the Coordinator and assisted with all applicable phases of the work. She was trained as a Facilitator and helped recruit people to be trained as Facilitators, organized Facilitator training, managed the system to connect frail elders with Facilitators, coordinated community presentations and distributed available printed materials.

Community Engagement

The coalition sent two professionals with extensive experience with frail elders and advance care planning to be trained and certified by the Gundersen-Lutheran Medical Foundation as trainers of facilitators of advance care planning (ACP). They subsequently conducted a series of trainings and presentations. Staff from each of the partner organizations were trained as SYW facilitators. People from organizations new to the project also attended the training. These included staff members from Longview, the Community Dispute Resolution Center, the Director of Admissions, Social Services, and a social worker at Lakeside Nursing Home and Rehabilitation Center; an attorney specializing in elder law; a financial planner; two social workers affiliated with the Pastoral Counseling Service; a psychologist; a church layperson; and a social worker from Kendal at Ithaca.

The coalition trained a total of 45 people and facilitators, exceeding their goal of 25-35 facilitators. Based on this success, they concluded that assisting the existing facilitators to improve their facilitation skills seemed the best use of project resources. All of the facilitators reported being more comfortable with advance care planning conversations following the training.

After the initial focus on developing this cadre of trained facilitators, the coalition also provided more than 30 presentations to the community. These were primarily to senior groups, congregate meal recipients, church study groups, senior residences, and caregivers. They also reached people through employer benefit fairs, community events and the media.

Professional Education

In addition to training facilitators, the coalition members presented a variety of workshops to assorted groups of helping professionals. For instance, staff provided a SYW workshop to the Tompkins County Health Department home care nurses and support staff; this training focused on phrases to use and when to introduce ACP. A presentation was also given on the topic “Advance Care Planning: Encouraging Conversations about Spiritual Values and Health Care Preferences” at the Pastoral Counseling Service’s conference.

The coalition developed training materials and a package for health and human service staff. This multi-media kit included CD/print/video /discussion/ blended learning modules of different lengths (10 min, 45 min, 2 hrs.).

Systems Change

The Tompkins County Coalition greatly enhanced local capacity to engage in ACP efforts in a variety of ways. They now have two trainers who are available locally, 45 people in agencies more able to help their patient/clients/families with ACP, people in the community wanting to complete ACP and excellent materials to support this interest. This intensive effort to train staff within local organizations to engage in ACP activities with their own program participants led to significant local systems change that will benefit people for a long time.

Summary

The Tompkins County Coalition successfully achieved their original goals. They managed to institutionalize Sharing Your Wishes project activities and resources into existing community organizations, thus accomplishing long-term systems change. In the first year, they strengthened their coalition, identified and helped develop existing materials, supported two local people to be trained as trainers, and began publicizing their activities. In the second year, they conducted workshops for helping professionals, encouraged more individuals to take advantage of the enhanced ACP resources, created and delivered presentations, and publicized the project. In their third and last grant-funded year, they extended the reach of all program activities and planned for sustainability.

Part D: Summary and Lessons Learned

All seven Sharing Your Wishes coalitions substantially contributed to increasing the adoption of advanced care planning within their communities. The coalitions faced a multitude of barriers that they still, to a greater or lesser degree, manage to overcome. Several cross-cutting themes emerged from the strategies they use to surmount these challenges. First, all of the coalitions were composed of interested persons from local organizations and the community-at-large. These coalitions existed prior to this project with a focus on improving care for older adults or on enhancing understanding about advance care planning. For the most part, the strength of their work came from involvement of their members supported by staff time dedicated to this project.

The coalitions' ability to identify and analyze their own unique community needs enabled them to adapt the program ideas to better serve their communities. In addition, their commitment to bring about long-lasting change allowed them to overcome challenges such as limited financial resources and turnover of staff and volunteers. This commitment was also a great asset to the coalitions as they sought to plan for program sustainability. And finally, the fact that most coalitions were well-developed, exhibiting maturity and highly developed stages of formation, allowed them to cultivate leadership within member organizations and achieve deeper levels of systems change.

Through their organizations, the representatives to the coalitions employed a collaborative process that involved working with stakeholders to identify and address various aspects of the advanced care planning process in ways that best suited their communities. They also worked with their counterparts in the other coalitions to share ideas and modify successful approaches to create what became Sharing Your Wishes. They developed a variety of program activities related to the specific assets and needs identified by their partners and **tailored available resources** (e.g. training curricula, educational materials, presentations, etc.) that were needed to deliver these programs. One example of this process was the way that Genesee County worked with first responders in the local Emergency Management System to refine the plastic packaging for individual personal health files for quick and easy access in the case of emergencies.

Three of the coalitions experienced turnover of coordinator staff (Cayuga, Genesee and Erie) and all experienced some change in coalition representation, but they overcame these challenges while continuing to provide education and resources to their communities. When these disruptions occurred over the course of the project, **commitment to “make a difference”** was the engine that enabled the coalitions to persevere and recruit other organizations and staff to maintain program momentum. Each coalition was made up of representatives from a diverse array of organizations that understood the often-negative consequences of the failure to plan ahead for future health care need for both consumers of services and practitioners alike. This understanding provided motivation for coalition members to go the extra mile in order to serve their local communities by raising awareness about issues associated with advanced care planning. When coalitions found themselves struggling they also had the advice and support of the other coalition coordinators to provide a different perspective and help them move forward.

The coalitions **provided services to a wide range of audiences** over the course of the project. While all reached out directly to older adults and their caregivers, they also geared many of their educational efforts towards health and social services professionals in an effort make a long-term

impact on service delivery systems. This strategy to institutionalize advanced care planning practices within local organizations allowed the coalitions to make the most of their limited resources while investing in long-term sustainability. Program participants included such varied groups as hospital and long-term care staff, social workers, clergy, health educators, program administrators, caregivers, and hospice staff. The challenge here was to convince health care providers that previous practices that often focused on completing forms could be enhanced with a focus on conversations and planning.

Coalition efforts resulted in **increased leadership capacity** within their communities. Over the course of the project, many program participants became more involved in the project, and ultimately transitioned into leadership roles. For example, throughout the project, most of the coalitions conducted train-the-trainer sessions aimed at training local volunteers to be advanced care planning facilitators. This cadre of facilitators became an excellent resource, maximizing the capacity of the coalitions to deliver services to many more community groups and individuals.

One factor that set the coalitions apart from one another was the way in which they administered the project, including the way they structured staff support. In most cases they used grant funds to pay for a part-time program coordinator by hiring staff or assigning an existing staff person from the organization that administered the grant. This approach provided start-up support but also fostered expectations among coalition participants about shared implementation responsibilities that led to support for long-term sustainability at the end of grant funding. In one case, the coalition was able to hire a full-time program coordinator. This coordinator was able to focus a great deal of time on start-up activities and led to an acceleration of activity early in the development of the program. While they were able to implement program components more quickly and in a broad and consistent way, this coalition faced a challenge in the last year of the grant funding to engage coalition members more actively to ensure program sustainability.

Overall, the efforts of the coalitions resulted in very positive impacts on their communities. Although the results from this effort are difficult to measure, the measures gathered, along with the anecdotal feedback, support the value of increased knowledge and awareness for the importance of planning ahead for health care decisions. The ability of the coalitions to harness the involvement of diverse stakeholders and focus their efforts toward increased awareness about advanced care planning was a major accomplishment. This legacy will continue to yield positive results over the coming years.

About the Community Health Foundation of Western and Central New York

The Community Health Foundation of Western and Central New York is an independent private foundation. It partners with people, programs and organizations working to improve the health and health care of western and central New York State. The foundation provides strategic investments, collaborative facilitation, stimulation of best practices, and advancement of health outcomes. Based in Buffalo, N.Y., with a second office in Syracuse, the foundation serves the western New York counties of Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans and Wyoming; and the central New York counties of Cayuga, Cortland, Herkimer, Madison, Oneida, Onondaga, Oswego and Tompkins. To find out more, visit www.chfwcny.org

The success of the coalitions in the development and implementation of Sharing Your Wishes involved many people and organizations working together. We would like to thank those who lead the effort in a variety of roles, as well as those who served as faculty and advisors.

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Sharing Your Wishes™

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