

Sustaining Sharing Your Wishes™

2009-2011

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Introduction

The Community Health Foundation of Western and Central New York (the “Foundation”) launched a project in 2005 to strengthen the capacity of selected community coalitions in order to improve the quality of care and quality of life for frail elders through increasing public awareness and stimulating practice and system changes in health care decision-making. The original six participating county coalitions that were identified and subsequently supported through Foundation funding were Allegany, Cayuga, Erie, Genesee, Niagara, and Tompkins. These coalitions were funded to implement the Sharing Your Wishes (SYW) project for three years, from 2005-2008 and their work continues today (see the summary report published in April 2008 for information on these project efforts).

As the work developed the project was expanded to include Onondaga, Cattaraugus, Chautauqua, Wyoming, Steuben, Orleans and Wyoming counties, but this report focuses on the original six participating counties.

Coalitions and the Foundation worked together to identify a number of existing best practices, including patient-centered care, palliative care, coordinated approaches to care as practiced by physicians, nurses and institutional health care providers; and community and family involvement in improvements in quality of care and quality of life. Because no existing program met the goals of the Foundation, the Sharing Your Wishes materials and approach were developed. In addition, a primary goal of the project was sustainability and, as a result, efforts were made throughout the duration of the project to institutionalize the innovative practices that the coalitions promoted within their local community organizations so they would become standard practices.

In an effort to assess the ability of the coalitions to sustain their successful efforts, the Foundation allocated resources to support impact tracking and reporting for three years after the project funding ended. This report documents the program

activities that were continued and describes the methods used to promote them over a three-year period, from 2008-2011. During this period, the six coalitions continued to track their impact and participate in semi-annual individualized coaching sessions. In addition the Foundation continued a limited learning community with periodic conference calls with all thirteen coalitions to support exchange of ideas and successful practices.

Methods

After funding for the project ended, all six SYW coalitions continued to engage their partner organizations in a variety of ways to implement the project. While each coalition varied in the intensity and scope of post-funding activity, all shared the common characteristic of having built the capacity among community members and organizations to sustain SYW activities, to a greater or lesser extent. The coalitions all reported in their summary reports that they expected to maintain some level of engaged SYW activity into the future. Specific examples of sustained programmatic activity include continuation of staff training for facilitators and changes in organizational policies to include advance care planning (ACP) in staff development. The following summaries describe categories of practices that were sustained by one or more of the coalitions during the three years after the grant funding terminated.

Community outreach and education reached thousands of community members through workshops, speaking engagements, video clips, health fairs, exhibits, and local events. Coalitions also used innovative methods such as placemats in diners and congregate meal sites, buttons, bookmarks, posters and other means to reach their audiences. After the grant funding ended, the coalitions continued these practices and, as a result, continued to widely distribute Sharing Your Wishes print materials. During their annual coaching sessions, many of the coalitions expressed their need for access to SYW materials for community distribution in future years. Each coalition chose different methods to engage their communities in efforts aimed at helping older adults plan ahead for future health care decisions.

Distribution of materials, such as Sharing Your Wishes materials and personal health files, was a significant feature of each coalition's community education effort. These materials have served as an important concrete tool that each coalition distributes using methods tailored to their own communities. Other methods to raise awareness about SYW include articles and notices placed in local newspapers, newsletters, placemats, and conference brochures.

Leveraging systems change in health care institutions and community organizations was one of the most successful tactics employed by the coalitions during the grant period. Specifically, this included providing training in various aspects of advanced care planning to employees and volunteers at hospitals, nursing homes, medical practices, hospices, and churches. Several coalitions forged innovative collaborations with higher education institutions that led to integration of advanced

care planning into a variety of courses. These capacity-building approaches proved to be extremely effective because after the grant period ended, these changes continued to yield programmatic impact with minimal staff investment from the coalitions. Connections to the Assuring Your Wishes™ Registry were another method the coalitions used to institutionalize permanent change in their communities.

Tracking impact and using data to measure progress was a practice employed by all coalitions both during and after the program funding period. From the beginning of the project, the Foundation emphasized impact tracking and each coalition was required to submit regular semi-annual project reports both during and after the funding period. The coaching sessions provided to the coalitions during the post-funding period included technical assistance emphasizing the importance of both qualitative and quantitative data collection. Teams were taught and encouraged to use effective impact reporting practices, including the collection, analysis and display of program participant data, as well as techniques for collecting narrative data to highlight positive program outcomes. Selected indicators that were identified in consultation with a group of physicians with geriatric and end-of-life care experience is tracked and run by the Hospital Executive Council in Onondaga County with the SPARCS data and provided to the coalitions periodically. The 2010 data will be added as an addendum to this report.

Specific Coalition Outcomes

These highlights describe practices that specific county coalitions sustained during the three years after the grant funding terminated. They are organized around the four categories identified above, including: community outreach and education, materials distribution, leveraging systems change, and tracking impact data.

Community Outreach and Education

Counties	Year	Number of presentations	Number of attendees	Completed Health Care Proxy (HCP)
Allegany	2008-11	6+15	250	323
Cayuga	2008-11	--	--	308
Erie	2008-11	1	27	8749
Genesee	2008-11	186	2,986	1219
Niagara	2008-9	9	187	--
Tompkins	2008-9	--	1,300	--

Note: blanks indicate data not collected by coalition.

Some examples of impact related to community engagement include:

- In **Genesee County**, Office for the Aging/NY Connects staff members, AmeriCorps Member and Long Term Care Task Force members attended a session on advance care planning. This staff development effort differed from the facilitator training in that it was intended to reinforce OFA/NY Connects and Long Term Care Task Force staff members' understanding of advance care planning, for themselves, for their loved ones and for the seniors and disabled individuals whom OFA/NY Connects and LTC Task Force agencies serve.
- **Niagara** offered a SYW module as part of the Niagara County Office for the Aging "Being Your Best – Golden Rule" program. This has been standardized to include: an introductory story to provoke discussion about the importance of having a health care proxy form, as well as the importance of choosing the right person as your agent
- The **Allegany**/Western Steuben Rural Health Network, Inc. formed a Speakers Bureau with certified **Respecting Choices**_(c) Facilitators to sustain the SYW program. The Speakers Bureau offers individuals a centralized resource for assistance and education, while providing support and flexibility to those participating.
- **Tompkins** has made progress with both Ithaca College and Cornell University in incorporating advance care planning into their practices.

- Ithaca College has participated in several outreach efforts, including: 1) a presentation to the Residential Assistants during their RA training in August, 2) package of materials for posting on RAs bulletin boards, and 3) outreach through the student-run HSHP and AGES clubs. They will also explore including SYW information in the new student orientation.
- At Cornell University, Gannett Health Services has assigned outreach around ACP to a particular staff member.

Materials Distribution

- **Cayuga** County prepared a column featuring advance care planning and SYW in an Aging Well column in their local paper, *The Citizen*, as well as an article for Health Care Decision Day.
- In **Erie** County, a 51% increase in material distribution that has occurred have been in response to requests from Independent Health, Hospice Buffalo, area hospitals, physician offices, clinics, the Erie County Department of Senior Services, and libraries.

Counties	SYW/ related materials distributed
Allegany	3,000
Cayuga	2,311
Erie	8,749
Genesee	3,527 (+15,000 health files)
Niagara	3,000 (est)
Tompkins	24,644

Coalitions in **Cayuga, Genesee, and Allegany** counties continued to implement a health file system that includes the SYW planning guide and other forms to help individuals have easy access to important medical information. Anecdotal responses of support were received from seniors and EMS providers. More than 20,000 health files were distributed in each of these communities during the project.

Four Coalitions include advance care planning facilitators trained in the methods of Respecting Choices, a program of Gunderson Lutheran in Wisconsin. These facilitators continue to work with individuals and small groups to help stimulate and facilitate conversations.

Counties	Facilitators currently trained
Allegany	101
Erie	27
Genesee	757(includes nursing students)
Tompkins	46 (+ 27 referral advocates)

Tompkins engaged in efforts to re-energize their trainers and, in doing so, found out more about the impact of SYW on their practice. A few of the responses to the question, “What have you done different as a result of SYW training?” included: “I bring it up more and in different settings, not just work.” “I have become this “go to “person for questions and materials.” “Sharing materials.” Feeling confident and inspired to discuss ACP.”

Leveraging systems change

Allegany County

As a result of the coalition’s partnership with Jones Memorial Hospital and Cuba Memorial Hospital in Allegany County, these health care providers continued to provide SYW materials to community members at various sites throughout the facilities including: emergency room, off-site clinics, laboratory, intensive care units, operating room waiting areas, and admissions. Hospitals verify advance care planning documentation; i.e. Health Care Proxy and hospital Do Not Resuscitate orders upon admission and electronic medical records reflect patients’ wishes.

Alfred University will be including a link to the SYW website with the Orientation Packets for its new students on an ongoing basis.

The SYW Coordinator presented a SYW Advance Care Planning Program tailored to a clergy audience. This annual event, sponsored by Jones Memorial Hospital features speakers and topics of interest to clergy in their role of counseling and support for families, often in crisis situations, at the hospital.

Cayuga County

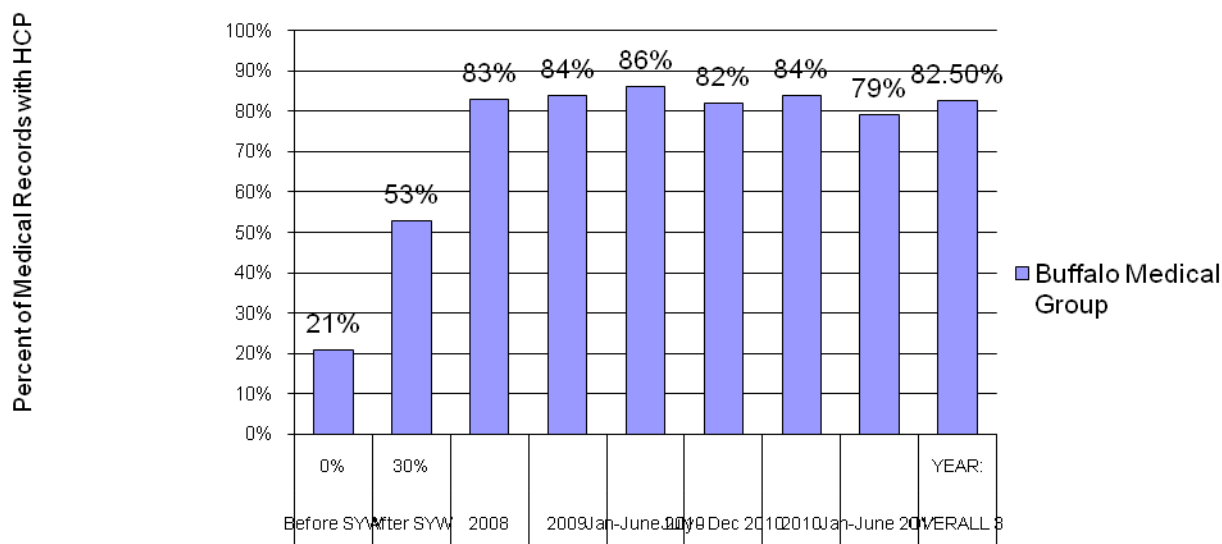
The coalition continued to work in a targeted way with a local nursing home, Mercy Health and Rehabilitation, to conduct chart reviews in an effort to better understand the role of advanced care planning in the development and implementation of care plans. This process will continue over the next several years in order to collect qualitative data on this and other issues related to the importance of nursing home staff to become more comfortable with the conversation and more attuned to the implications of choice.

Erie County

The Erie Coalition continued its work with clergy, health ministry team, and other members of faith based groups who were trained in advanced care planning.

The coalition also worked with medical practices. Mid-level professionals in the practices were trained to hold conversations about ACP with patients. Through their work, a protocol was developed for discussion and implementation of ACP. They measured change in the usage of the SYW protocol over the six year period from 2005-2011. The percent of advance directives increased to 83% in 2008 and has maintained at this higher level since then. (See bar graph below).

Erie SYW in Medical Practices



Genesee County

The coalition worked with the Genesee Community College Nursing program to include Sharing Your Wishes in a course required for all nursing students. This collaboration also led to an expanded effort to improve the geriatric education experience for all nursing students. GCC Geriatric Clinical Rotation is a New York State Department of Education approved curriculum and has been very successful in increasing the knowledge and skills of students in regards to engaging older adults in planning ahead for future health care decisions.

The GCC Nursing program has made the Gundersen-Lutheran Facilitation Training a core requirement which has allowed student to graduate as Certified Advance Care Planning Facilitators. Students have reported that having that certification on their résumé has helped them in their job search and has made them very attractive to future employers. The Nursing program has grown in the past year, doubling its

enrollment, which means that the impact of embedding advance care planning facilitation into the curriculum will impact an even greater number of future nurses for many years to come.

Niagara

The SYW component continues to be offered as part of the Niagara Council for Older Adults in Niagara County’s programming. Presentations covering the materials are made to various senior groups as well as at agency meetings. The Council is now becoming known as a “go to” program for these materials and presentations and has received requests for both, presentations and materials.

Listed below are some, but not all, of events/venues that SYW/AYW materials were presented to the last six months:

- They have begun the process of distributing the 1,000 Personal Health Files that they partnered with Niagara County’s NY Connects program to create. This was done with the support of two local agencies that funded the additional materials needed. They tentatively have the support of one of the agencies to support the future growth of this new program.
- The council received six requests for presentations and materials at various senior groups and senior housing units.
- They participated in 3 senior health fairs.
- They presented the SYW materials to a benefits coordinator at a local senior residence and he is interested in having the materials on hand for more than 200+ residents. He found the materials very user friendly.

Tompkins

Data from Tompkins County’s annual survey of community organizations yielded this valuable information about the categories of materials that were being distributed.

Which of these materials do you distribute on a regular basis? (Check all that apply)	
Options	Response Percent
Your own agency’s materials	23.5%
Form from the NYS Department of Health site	35.3%
Sharing Your Wishes (SYW) Guides (smaller)– includes health care proxy form	64.7%

SYW Information Booklets (larger)	52.9%
SYW Health Proxy Cards (bi-fold, with responsibilities)	35.3%
Assuring Your Wishes packets (info card, authorization form, envelope)	5.9%
Excellus ACP booklets	11.8%
FIVE WISHES booklets	29.4%
“Hard Choices For Loving People” booklets	23.5%
New York State Attorney General guides, “Planning Your Health Care In Advance: How to Make Your End-of-Life Wishes Known and Honored”	5.9%

In an attempt to determine how practice and patient care changed because of increased awareness of advance care planning, Tompkins asked one nursing home to respond to questions about impact to care. In response, they reported this success story:

- *Staffs at a large senior residence (McGraw House) are very concerned that not all residents have completed forms. So they sent a letter to every resident inquiring if they have advance directives including health care proxy, power of attorney and will. The staff was pleasantly surprised to find that, when asked in writing, more residents than they knew about do have documents and subsequently presented copies to the staff for safekeeping in office files.*

Tompkins’ continued effort to engage the faith-based community resulted in this anecdote:

- *At the annual meeting at Cayuga Medical Center, a pastor who does some support of patients in the hospital commented that they are using this great material for thinking about health care wishes, and that he has shared it with other pastors in the region. He didn’t know that we (the Health Planning Council) were the lead on this project; he had received the materials from another minister. [Tompkins]*

Tompkins County’s training tool kit continues to be posted on the Sharing Your Wishes website supported by the Foundation as part of the community resources tool kit and is available to all of the coalitions. The tool kit was developed with input from Niagara and Cayuga coalitions and all thirteen coalitions participated in a beta test of the materials. Tompkins has also been contacted several times to provide information about their experience. These include training and provision of the SYW binders to new coalitions. They have also received a request about Assuring Your Wishes from the chief information officer in Columbia Memorial Hospital in Hudson, New York. In response, they provided information about the development and roll-out in Tompkins County.

Cattaraugus and Genesee coalitions established license arrangements with the Assuring Your Wishes Internet Registry.

Tracking Impact

The **Cayuga** County coalition measured change over time in the number of health care proxies (HCP) on file in three nursing homes in their county and results revealed that two out of three of the facilities had increased rates of completed HCPs. The chart below documents these changes.

Agency Name	% with HCP 2005	% with HCP 2006	% with HCP 2008	% with HSP 2011
Cayuga Nursing Home	61	48.1	80	78
Faatz-Crofut Home	22	24	64	30
Finger Lakes Center for Living	78.4	81.5	71.8	69

Erie County's coalition worked with a health care provider, Buffalo Medical Group to collect qualitative data regarding the impact SYW has had on the patients and families they serve. The following are example anecdotes:

"After completing my own HCP, I encouraged my family to do it also. Their refusal to do their HCP's made me feel that I was making it easier for them, but they were not making it easier for me." Nurse practitioner

"It is easier to consider doing a HCP when you are well than when you are sick. When you are sick, a HCP reminds you and your family that you have a serious illness." Patient

"It was very helpful. I'm at peace." Patient

"It is better to have a loved one making decisions for you than a stranger in the hospital." Patient's spouse

In **Niagara County**, a social worker at one of the senior facilities that had received materials was asked to respond to the following questions:

- How have these materials helped your organization? Her response was, "These materials have helped greatly. Our residents and families report that it is easier to make decisions when they are able to read over the information at their leisure and share it with other family members."
- Are you making sure that each resident/client has a HCP in their file? "Absolutely!! They're not only given out to residents but also their families." She also stated, "I find these packets extremely beneficial."

Discussion/Conclusions

The Sharing Your Wishes project involved community coalitions working to stimulate change in practice among providers in their communities and among the public. Their efforts to gather data measuring program activities and the impact of the project varied greatly. Each coalition received coaching sessions following submission of their six month reports in an effort to provide technical support on their sustainability efforts as well to assist them in tracking the impact of the project. These continued efforts to gather impact data over the past three years have helped clarify ways that this project was able to sustain activity over time and how it was able to change practices at the individual, organizational and community level through these continued efforts.

While all the coalitions tracked their efforts in individualized ways that were tailored to their own communities, they all did a thorough job of tracking the number of inquiries, materials distributed, and presentations made. In addition, they also tracked qualitative data, such as quotes and anecdotes, which paint a more complete picture of what is now different in their communities as a result of this effort. Through a series of snap shot measures and the gathering of data and comments from a variety of sources, we are able to see that individuals who were touched by the project have a greater knowledge and comfort level about advance care planning. They understand why it is important and the issues that need to be considered. While it is particularly difficult to know exactly how many older adults actually had conversations about their wishes with their families and health care providers, it is clear that these coalitions are having a lasting impact on them and their communities.

We learned that while much of program activity focused on individuals, engaging physicians, volunteers, as well as other health and community-based providers was essential for success and sustainability. Every project included some focus on engaging these individuals and organizations in an effort to enlist them in efforts to carry activities from this initiative forward. These capacity building efforts resulted in programmatic activities being institutionalized within many different community organizations in the form of standard practices, thus insuring their continuity after funding was no longer available.

After project funding ceased, all six Sharing Your Wishes coalitions profiled in this report continued their efforts to stimulate change in practice among providers in their communities and among the public. This report contains samples of anecdotes and quotes from a variety of sources that demonstrate how the coalitions touched the people in their communities in meaningful ways.

Analysis of these measures indicate that the coalitions made significant impacts on their communities, which include: 1) a greater knowledge and comfort level about

advance care planning at the individual level, as well as 2) changes in organizational practices that support a greater awareness of advance care planning.

In their own unique ways, each coalition continues to engage their communities to carry this effort forward. Impact data that was collected over the past three post-funding years has helped us understand how this project has, and will be, sustained over time and how it has changed community practice through these continued efforts. These efforts also provide the opportunity for the larger group of counties later added to the project (Onondaga, Cattaraugus, Chautauqua, Wyoming, Steuben, Orleans and Wyoming) to benefit from the experience of the original six coalitions.