Working Together: Organizing and Building Coalitions

The Conversation Project

May 15, 2019
WebEx Quick Reference

Welcome to today’s session!

Please use Chat to “All Participants” for questions

For technology issues only, please Chat to “Host”

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)
Ice Breaker Question

Type into the chat box your response to the following:

*How did you hear about this call?*

Make sure you send your message to “All Participants.”
Where are you located on the map?
The Conversation Project Field Team

Patty Webster
Improvement Advisor

Naomi Fedna
Project Coordinator
Call agenda

- Framing
- Community highlights: Three examples of grassroots organizing and coalition building
- Questions and discussion
- TCP additional resources/updates
- Wrap up
Initial reflections - Chat

What brought you to this call?

• General learning? A burning question(s) you want to explore? Challenges you want to discuss? Successes you want to share?

What experience do you have with building coalitions or networking with others?

• Newbie, Seasoned, Somewhere in Between?
A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.

the conversation project
Strategy for Creating Cultural Change

- **Awareness**: National media campaign and community engagement events

- **Accessible**: Tools to help people get started

- **Available**: Bringing TCP to people where they work, where they live, and where they pray
Building Local Community Engagement
Recap: Getting Started Questions

- Who do you want to reach? And by when?
- What do you want to support them to accomplish? What actions?
- How do you want to reach them?
- What is the context of this topic for population you’re trying to reach?
- Who else is already doing this work in your community? Who else could you be working with?
- Who are respected leaders or organizations that could help you advocate for the importance of this work?
- Who will be responsible for actually doing this work in your community?
- How will you measure successes and challenges?
- How do you plan to reach diverse groups of people in your community?
- What can you do by next Tuesday?
Organizing Theory of Change

Change:
Using this power to address the challenge the constituency is called to face

Power:
Building a community around that leadership to create power

People:
Recruiting and developing leadership

... people acting together to change the status quo

Source: Institute for Healthcare Improvement’s Virtual Course, Leadership and Organizing for Change
Organizing as a strategy

- Organizing starts with connections, relationship building, mutual trust
- Organizers bring individuals together to create collective capacity that’s not present when individuals act alone
- Organizing can accelerate your success
Possible Community Partners

- Assisted Living Facilities
- City Employee Retirement System
- Dept. of Public Health, Mental Health, Behavioral Health
- Elected Officials
- EMT providers
- Estate/Legal entities (elder law, local bar association…)
- Employers
- Faith-based organizations, clergy, chaplains ministerial associations
- Financial community (banks, CPA firms, financial advisors)
- Health plans/insurers
- Home care/VNA
- Retirement communities and home owners associations
- Homeless shelter/services
- Hospice
- Hospitals/Health systems
- Local resources: libraries, Chamber of Commerce, Lion/Rotary/Elks Club…
- Media channels (local, state, regional)
- Medical/Nursing/Hospital Association
- Nursing homes, rehab facilities, long term care
- Physician office practices/primary care
- Prisons/jails
- School District – employee benefits, Parent Teacher Organizations
- Senior Advocacy Organizations/Elder Services (Area Agency on Aging, senior center, transportation services, meals on wheels)
- Universities – students, faculty, alumni
- Veterans Services
“If you want to go fast, go alone. If you want to go far, go together.”
—African Proverb
Andrew Ingall
Co-director, ReImagine
End of Life
Our Purpose

Reimagine End of Life aims to transform our individual and collective experience around death, dying and *living*. 
Our Vision

Taboo → Acceptance
Isolation → Community
Anger → Love
Pain → Art
Loss → Celebration
Our Method

Reimagine hosts community-based programs that bring a week of vital discussion, education, inspiration, and interpersonal connection to cities around the world.
Our 4 Pillars

Arts+Culture
Health+Medicine
Design+Technology
Faith+Spirituality
Reimagine New York City 2018 encompassed more than 350 events over the course of one week, including:

- 24 Advance Care Planning
- 28 Music
- 31 Film Screenings
- 27 Dance/Movement
- 37 Literature
- 62 Interactive Rituals
Changing attitudes towards death and life.

91% of surveyed attendees said Reimagine helped make talking about death easier.

76% of surveyed attendees said their experience at Reimagine led to new conversations on life and death.

89% of surveyed attendees said that Reimagine made them more grateful for their lives and those around them.
Who goes to Reimagine?
Reimagine is for everyone.
Festival attendees are intergenerational.

- 5.9% 75+ yrs
- 9.3% 65-74 yrs
- 18.3% 45-54 yrs
- 25.6% 25-34 yrs
- 18% 35-44 yrs
- 3.5% 1-24 yrs

Our social media followers also are intergenerational.

- 9% 65+ yrs
- 1% 1-24 yrs
- 17% 55-64 yrs
- 23% 35-44 yrs
- 19% 25-34 yrs
- 30% 45-54 yrs
And a few words from festival attendees...

“What really struck me was the beauty of the community assembled at each event I attended.”

“We were instantly united in the universality of our own mortality.”

“We were able to feel and think deeply together about loss, pain and death. It was very beautiful.”

“It reminded me of the generosity and complexity of souls within the strangers in my midst every single day.”

“Over and over I found myself connecting with and expanding upon my own thoughts about life and death, meaning, message.”

“The people I met, the fact that there are people who want to reimagine end of life, love and memories the way I do. I thought I was alone.”
THANK YOU
Marisette Hasan, RN, BSN
President & CEO, The Carolinas Center
Co-Chair, CSI Advance Care Planning Workgroup
mhasan@cchospice.org

John Ropp III, MD, MBA
Chairman, South Carolina Medical Association
Chairman, CSI
jropp97@gmail.com
South Carolina Coalition for the Care of the Seriously Ill (SC CSI)

Transforming Advance Care Planning through Friendly Processes
How Did CSI Become and Effective Coalition?

✓ Identify and recruit champions who have a passion for the work (clinicians, providers, payers, consumer advocates, etc.) - who is NOT at the table who should be?
✓ Organize a structure that promotes engagement and participation of all members - open meetings held regularly at the same central location
✓ Collaboration and Consensus - takes time to build trust among members (years!)
✓ Commitment from Core members - time, services, “in-kind” offerings
✓ Seek funding that will help start and sustain your work - start small and show commitment and early successes (payers, health systems/providers, foundations)
✓ Grass roots community engagement of diverse groups - get out town! Go to where the people are in civic groups, churches, annual meetings, etc.
✓ Identify and address conflicts of interest as soon as possible
South Carolina Coalition for the Seriously Ill

History and Timeline

- Awarded BlueCross BlueShield Foundation of South Carolina Grant for Advance Care Planning (ACP) - Dec. 2017
- ACP Grant Activities Launched in 5 Geographic Communities - July 2018
- POST Legislation Introduced and Referred to House Committee - Jan. 2018
- 3-Year Strategic Plan Developed by Palmetto Care Managers - June 2017
- Physicians Order for Scope of Treatment (POST) 3-Year Pilot - 2014
- South Carolina Coalition for the Care of the Seriously Ill (CSI) Established - 2010
- 3-Year Strategic Plan Developed by Palmetto Care Managers - June 2017
- POST Legislation Introduced and Referred to House Committee - Jan. 2018
- ACP Grant Activities Launched in 5 Geographic Communities - July 2018
- POST Legislation Reintroduced - 2019
My Life My Choices
Community-based ACP Initiative

- Utilizes **Respecting Choices® Implementation Framework**: Community Engagement, System Redesign, Education and Training and Quality Improvement
- Leverages strengths and priorities of **key partners**
  - AARP SC, SC Hospital Association, SC Medical Association, USC Core for Applied Research & Evaluation
- Implemented in **five (5) geographic areas**
- Primarily focused on **vulnerable and underserved populations**
Collective Impact
Key Metrics (July 2018 – March 2019)

- 4,194 Community Members Educated
- 442 Providers Trained
- 748 ACP Conversations Conducted
- 257 Advance Directives Completed

- 79% Percentage of Participating Community Members Willing to Have the Conversation
- 84% Trained Healthcare Professionals Expressed Greater Confidence in Conducting ACP Conversations
Next Steps
Sustaining Coalition and Grant Work

- Formalize CSI structure and charter
- Investigate grants and additional funding streams
- Continual align with strategic objectives of key partners
- Maintain core mission
Thank You

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@MLMC_SC
www.mylifemychoices.org
www.scpost.org
@MLMC_SC
Micki Jackson
ACP advocate, volunteer & grassroots organizer

Bellingham, WA
Rebecca Rech Cutler, BSN, RN, CRRN (Certified Registered Rehabilitation Nurse), CHPN (Certified Hospice and Palliative Nurse).

Rebecca has been a RN for 30 years with 15 years of Home Health and 5 years of Hospice experience.

Bill Lombard, MD

Nephrologist and medical director of the DaVita Mt. Baker Kidney Center. Dr. Lombard has been practicing in Whatcom County for over 35 years.

"Helping others understand what care and treatments you would want if you were unable to communicate yourself is the biggest gift you give yourself as well as those you leave behind. Help us make sure your wishes are known and understood and mention to your doctor that you’d like to complete an advance directive."

- Scott Foster, MD, MPH, Chief Medical Executive, PeaceHealth Medical Group

"Realities of Advanced Medical Interventions” supports good decision-making before an accident or serious illness occurs. This presentation is a conversation starter to help you prepare to talk to your family, friends and to your doctors so that you can make your healthcare wishes known.

- Micki Jackson, Advocate for Advance Care Planning & Community Palliative Care

THE REALITIES OF ADVANCED MEDICAL INTERVENTIONS

Bill Lombard and Rebecca Rech Cutler will present in frank terms the meanings of advanced medical interventions, and what their outcomes could mean for patients in the short and long term. Advance care planning, advance directives, and the importance of palliative care are discussed. These interactive sessions include Q&A.

2019 Quarterly Schedule

St. Luke’s Health Education Center,
3333 Squalicum Parkway

March 6, 2019, Wednesday, 6:00PM
Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

June 5, 2019, Wednesday, 6:00PM
Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

September 4, 2019, Wednesday, 6:00PM
Presenter: Rebecca Rech Cutler, BSN, RN, CRRN, CHPN

December 4, 2019, Wednesday, 10:00AM
Presenter: Bill Lombard, MD

Resource Contacts for Assistance with Advance Care Planning

Hilary Walker
PeaceHealth Program Coordinator for Advance Care Planning | Palliative Care
360-752-5267 | hwalker@peacehealth.org

Advance Care Planning Volunteers & Facilitators
Whatcom Alliance for Health Advancement
360-788-6594 | info@whatcomalliance.org

Information on Realities of Advanced Medical Interventions

Micki Jackson, Coordinator
360-201-7840 | micki98226@aol.com
"Now I know, what I didn't know, is what I need to know."
- Mike Diehl, DIEHL FORD (member)

Examples of Collaborations

Whatcom Transport Authority for NHDD

Rotary Club presentations

Health Ministries Network

Local Subaru Dealership for NHDD
Example of How Grassroots Grows

“I’ve Got Mine” Campaign Template
(Beginning efforts in SW WA to customize for individuals and groups ready to share the message and LEAD BY EXAMPLE)

Thanks to Marie Eaton and Team for the video

Thanks to Micki Jackson, Whatcom County community advocate, who conceived the “I’ve Got Mine” campaign for PeaceHealth Medical Group, and to all the ACP volunteers in her community and throughout Washington State
Q&A and Discussion
Boston Theological Interreligious Consortium (BTI) Life Long Learning conference

Organizers: Co-sponsored by Boston Theological Institute, with support from The Conversation Project and the Massachusetts Serious Illness Coalition (MASIC), BCBS

- **Aim** to reach clergy in formation, faculty, alumni, and clergy in practice, lay leaders with an interest in how to bring Advance Care Planning to their faith institutions.
- **Motivational pull** - theological grounding for “why do it.”
- **Structured** for maximum inspiration and practical information
- **Stories shared** about how other congregations have done this successfully
- **Tools for action** including the Hello Game, The Conversation Project’s Starter Kit guide

TCP Additional Resources and Updates
# Upcoming Community Calls

The next Conversation Project Community Call will take place on:

**Wednesday, June 19th, 3:00-4:00 PM EDT**

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td>Wednesday, June 19th, 3:00-4:00 pm EDT</td>
<td>Community Planning 101</td>
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<tr>
<td>Wednesday, July 17th, 3:00-4:00 pm EDT</td>
<td>Community 201: Lessons on Messaging from the Massachusetts Coalition for Serious Illness Care</td>
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<tr>
<td>Wednesday, Aug 21st, 3:00-4:00 pm EDT</td>
<td>Special Interest: Conversation Sabbath</td>
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TCP Conversation Champions Map

- Search, connect/network and learn together

https://theconversationproject.org/get-involved
TCP Get Involved Page: Community Engagement Resources

- Get started
  - Community organizing guide and resources
  - Case studies
  - Template for tracking progress, suggested metrics

- Promote your message
  - Sample promotional materials (PSAs, ads)
  - Social media toolkit

- Host an event (planning, publicizing, facilitating, evaluating)
  - Invitations and agendas for events
  - Press release and flyer templates
  - Slide deck, videos, materials to bring
  - Movie screening guides

https://theconversationproject.org/get-involved
New Resources

- How to Talk to Your Patients about End-of-Life Care: A Conversation Ready Toolkit for Clinicians
  [http://www.ihi.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx](http://www.ihi.org/resources/Pages/Tools/Conversation-Ready-Toolkit-for-Clinicians.aspx)

- 6 Go-to Health Care Resources: Respecting End-of-life Care Wishes

- Resource Recap and Highlights of the Month: April 2019
Write a Letter to Your Loved One

- Write a letter to your loved one(s) about what matters most to you and email your letter to conversationproject@ihi.org

  “And for God’s sake, have mercy and trim my chin and upper lip hairs.”

  “No heroics. Listen to your mother.”
We want your feedback!

After this call you will be redirected to a Survey Monkey form.

Please take a few moments to answer questions that will ask you to rate the overall effectiveness of this call.

THANK YOU!
Thanks and appreciation

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults