

Coordinating Our Forces: State Pediatric Palliative Care Coalitions in Action



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Disclosures



THE PRESENTERS HAVE NO RELEVANT
FINANCIAL RELATIONSHIPS TO
DISCLOSE.

Goals and Objectives



1. Explain the role and reach of State Pediatric Palliative Care Coalitions
2. Describe at least 3 stakeholder engagement strategies for building and mobilizing your state coalition
3. Identify at least 5 action steps state coalitions can take to enhance pediatric palliative care awareness and access

What is a Coalition?



A group of people, groups, or countries who have joined together for a common purpose

-Merriam-Webster dictionary

An alliance for combined action

- Oxford Dictionary

We are UNIFIERS, able to bring together the diverse perspectives of families, hospitals, local providers, payers, communities, churches and other stakeholders towards a common vision.

We are ADVOCATES, challenging the existing healthcare system for children with life-threatening conditions and insisting that public funding for healthcare services be in alignment with their unique needs.

We are REVOLUTIONARIES, speaking out on behalf of those too little or too sick to speak for themselves.

We are PARTNERS, aligned with and inspired by one another. Together we are stronger. Together we will succeed.

A Short History Lesson



1997- 2003
Community
Partnerships to
Improve End-of-
Life Care

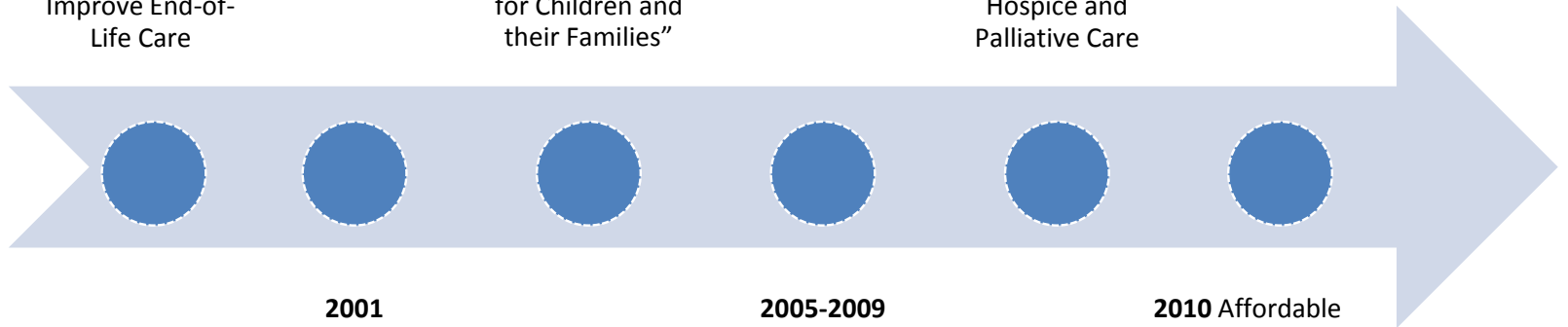
2002
IOM Report
“When Children
Die: Improving
Palliative and
End-of-Life Care
for Children and
their Families”

2006 Minnesota
National Forum
on Pediatric
Hospice and
Palliative Care

2001
ChiPACC
Model/Centers
for Medicare
and Medicaid
Services (CMS)

2005-2009
Initiative for
Pediatric
Palliative Care

2010 Affordable
Care Act
Pediatric
Concurrent Care
Provision 2302




Audience Survey



- ☐ My state/region has no Coalition and no known interested parties.
- ☐ We have an interested group of people, but don't know how to begin.
- ☐ We have a Coalition, but have a hard time sustaining activity.
- ☐ We have an active Coalition, but can always learn more.

A Tale of Two Coalitions



Dedicated to
improving
children's access
to community-
based palliative
and hospice care
services through
advocacy,
program
development and
education.



CHILDREN'S HOSPICE
&
PALLIATIVE CARE
COALITION

A Division of the Coalition for
Compassionate Care of California
www.coalitionccc.org



Our Mission:
Provide resources to
families, volunteers
and medical
professionals caring
for children with
life-limiting
illnesses.

Our Goal: Provide a
clearer path for
children and their
families coping with
this difficult, life-
altering experience.



Lighting the Way in Pennsylvania.

www.ppcc-pa.org

The Current State of Pediatric State Coalitions



Established:

- **Greater Illinois Pediatric Palliative Coalition - GIPPCC**
- **Ohio Pediatric Palliative Care and End of Life Network**
- **Kansas Hospice and Pediatric Palliative Care Coalition**
- **Alliance Kids (Maryland)**
- **Pediatric Palliative Care Coalition of MN**
- **Pediatric Palliative Care Coalition of NC**
- **Texas Pediatric Palliative Care Consortium**
- **Hospice and Palliative Care Association of New York State**

Formative:

- **Children's Palliative Care Coalition of Michigan**
- **Pediatric Palliative Care Coalition of SC**

The Power of Coalitions



Collaborative Partners:

- Share a common goal.
- Put their individual agendas aside for the greater good.
- Commit time and resources to a mission and vision bigger than their individual interests.
- Understand that there is political strength in numbers and represent a voting block of individuals, including parents and healthcare professionals, who are committed to improving care for children.
- **Rise above the Noise!**

The Power of Coalitions



Opportunities to:

- **Educate** – Healthcare Professionals, Families, Communities
- **Advocate** – Local, Regional, State and Federal
- **Innovate** – Develop programming, Build collaborative partnerships, Envision
- **Perpetuate** – Expand access to Pediatric Community and Hospital-based Palliative Care, Concurrent Care, Hospice Care, and Home Health Services

What Are the Barriers to Formation?



Barriers

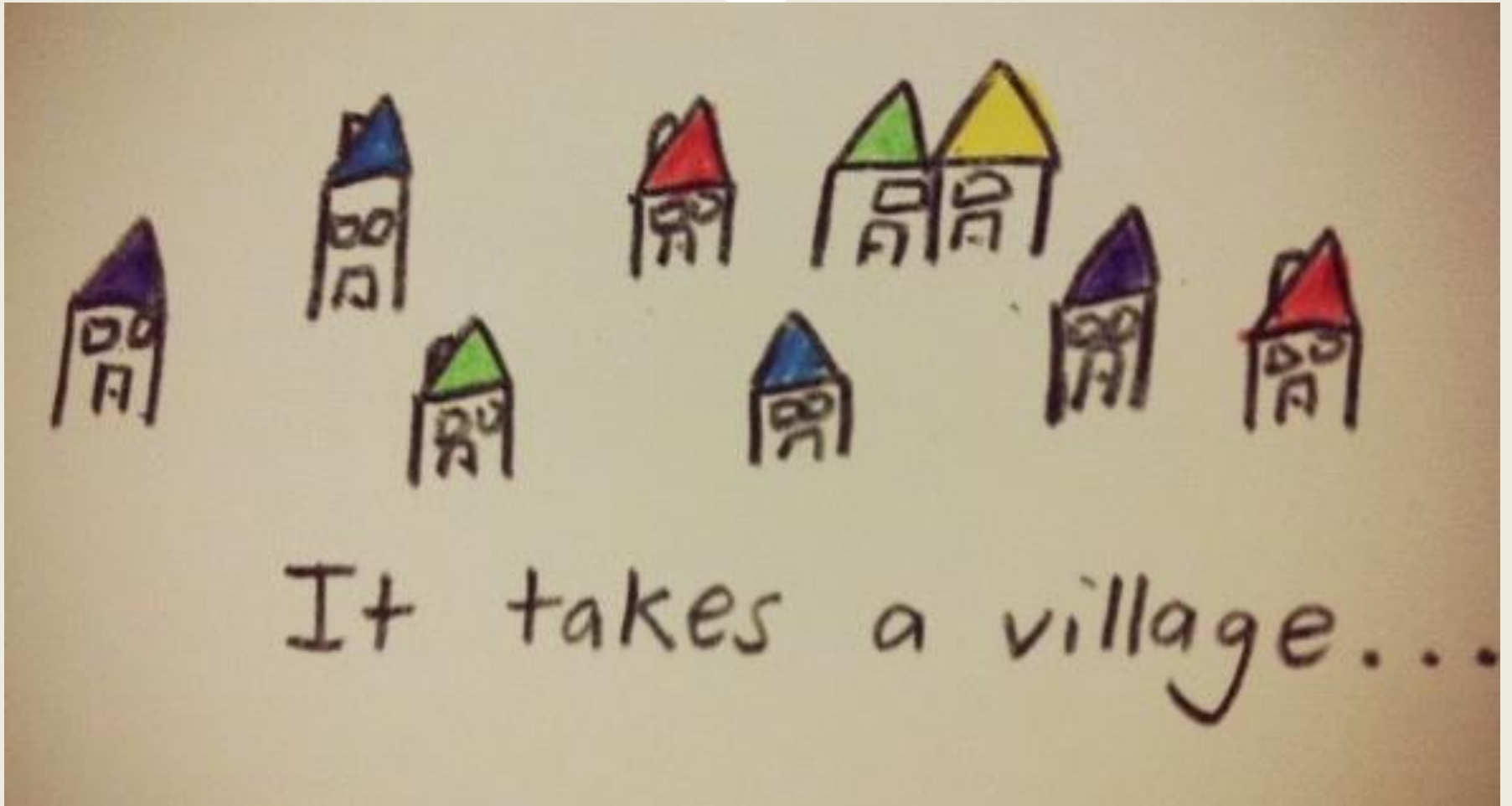
New Beginnings



***“ALL SOCIAL MOVEMENTS ARE FOUNDED
BY, GUIDED BY, MOTIVATED AND SEEN
THROUGH BY THE PASSION OF
INDIVIDUALS.”***

MARGARET MEAD

Build Your Village



Find Your Focus



Mobilize Your Troops



Build it to Last



Sustainability Considerations



CREATING VALUE

- ✧ Value to participants/members
- ✧ Value to interested stakeholders
 - Families
 - Patients – children and young adults, as appropriate
 - Health care personnel & systems
 - Payers
 - Legislators
 - Individuals
- ❖ Value to community at large

Sustainability Considerations



Needs assessment

- ❖ Are you responsive to the needs of your stakeholders and members?

Structure

- ❖ Independent vs alignment
 - Strong state or regional institution or association
 - 501c3 status
- ❖ Internal organization
 - Mission, vision, bylaws/guidelines, Board of Directors

Staffing

- ❖ Volunteer army vs paid staff

Programming

- ❖ Education – formal, informal
- ❖ Direct service
- ❖ Curriculum/resource development

Measurable outcomes

Sources of Funding



- ☐ Grants for programming/research
- ☐ Support from parent organization
- ☐ Fees for educational programming
- ☐ Membership fees
- ☐ Sponsors for conferences and events
- ☐ Event fundraising
- ☐ Community fund raising
- ☐ Sale of resources
- ☐ Donor cultivation and solicitation

Monitor Your Success



What Makes a Good Measure?



- Uniform
- Easy to collect
- Based on best-available evidence
- Allows comparisons across institutions, organizations, agencies, groups
- Relevant to your coalition & stakeholders

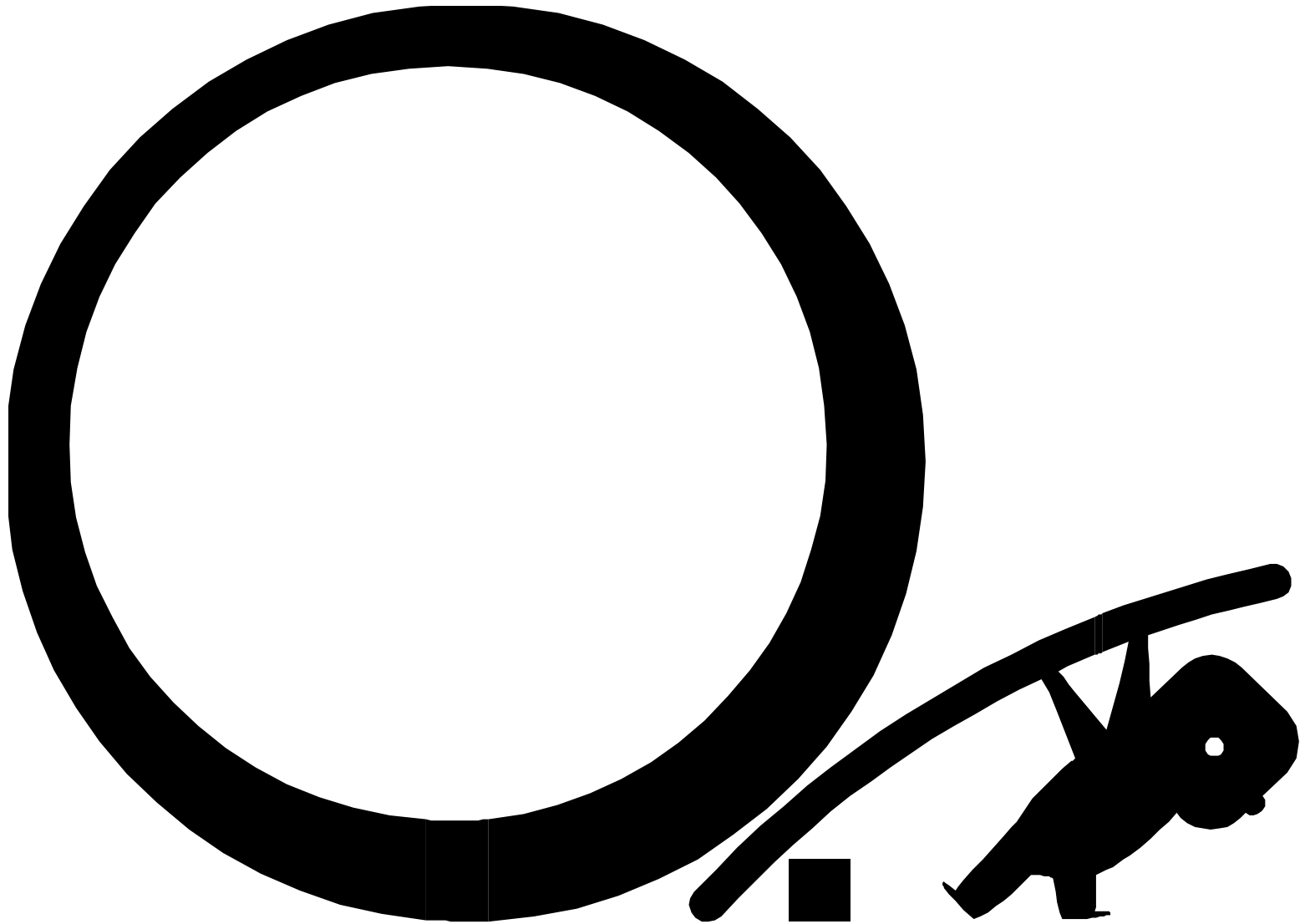
Questions to Ponder



How much did we do?

How well did we do it?

Is anyone better off?



Group Exercise

**The best time
to start was
yesterday.**

**The next best
time is NOW.**

Stay In Touch



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