

**New York State's
CHI PACC®
Demonstration Project**

Needs Assessment Summary
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Modeled after the *Children's Hospice International Program for All-Inclusive Care for Children and their Families® (CHI PACC®)* and underwritten by the U.S. Government grant to Children's Hospice International for its *CHI PACC®* Program

Background

- How would you describe the needs of a child with a potentially life limiting illness?
- In many cases, words like “Complex”, “Overwhelming”, or “Heart-rending” may come to mind.
- Such descriptions may arouse us to action, but what kind of action is possible without a more detailed knowledge of the needs of children and their families?

Background

- We looked to the scientific literature for help.
- We found that some models of needs have been proposed for people in general.
- But we do not yet have an agreed upon model of child or family palliative care needs.

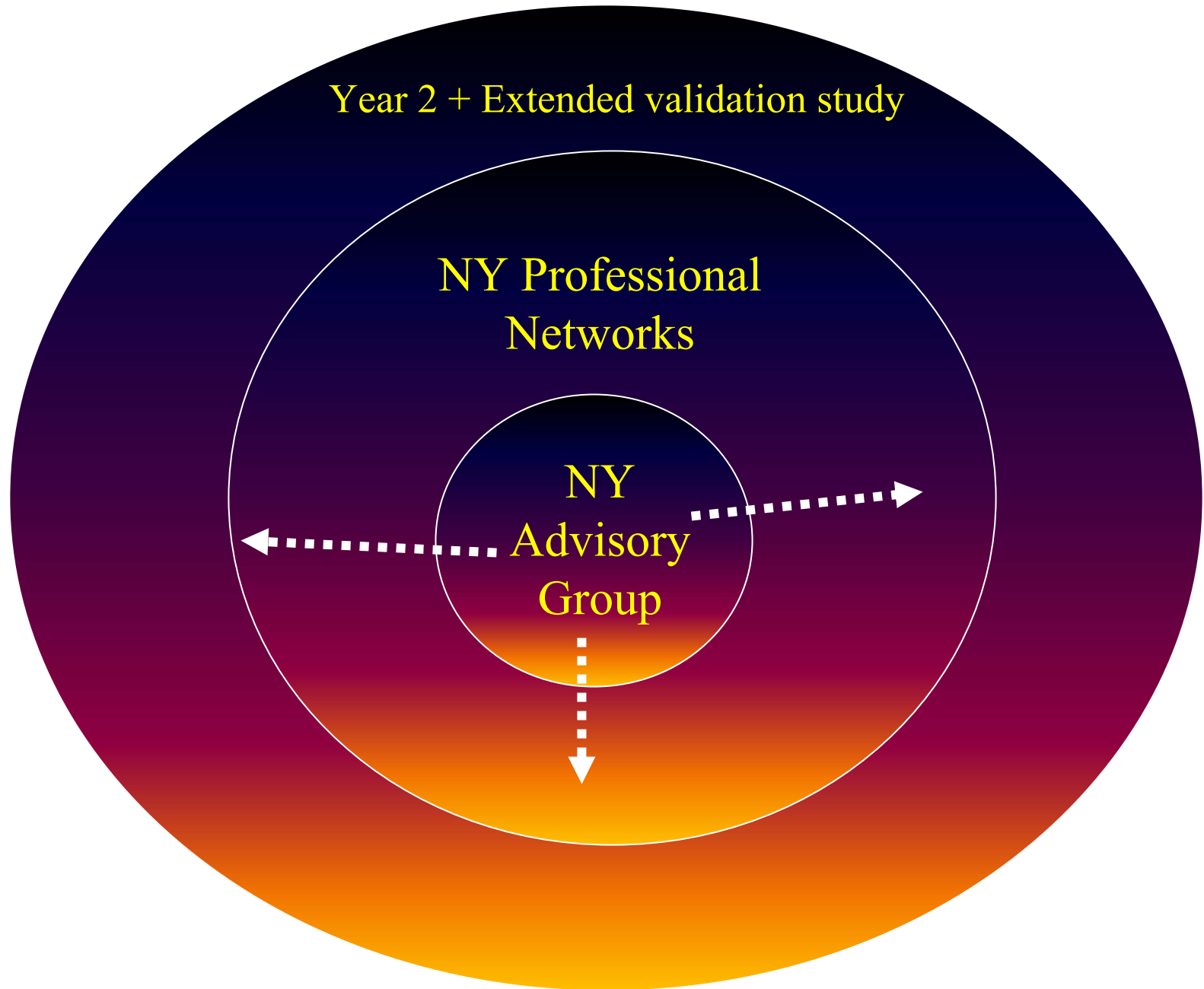
What should the scope of the Needs Assessment be?

- Multiple perspectives
 - Should child and family needs be considered separately or together?
 - What level of assessment should be conducted: world, national, state, or local perspectives?

Who knows about children and families dealing with life limiting illness?

- Children & families
- Care providers
- Health program administrators
- Related professionals (advocates, academics, foundation members, government employees, health maintenance organizations, etc.)

Sampling Strategy



How Can We Find Out What the Experts Think?

- Numerous options for data collection
 - Survey, Focus Group, Interview, or Web-based data collection?
 - Concept Mapping
 - A research method developed by Professor William Trochim of Cornell University.
 - The method is supported by a computer program (The Concept System), and Concept Systems, Inc. of Ithaca, NY.
 - Studies can be conducted on the Internet

What Is Concept Mapping?

Concept mapping is . . .

- A structured process
- Focused on a topic or construct of interest
- Involving input from one or more participants
- Produces an interpretable pictorial view (concept map) of their ideas and concepts and how these are interrelated.

Results

Top Ten Children's Needs (highest importance ratings)

1	Effective pain management	5.00
2	Consistent pain assessment	5.00
3	Comforting atmosphere with pain control	4.91
4	Quality of life	4.91
5	Prayers	4.73
6	Love	4.73
7	Accurate assessment and effective treatment of pain and non-pain symptoms	4.73
8	Reduction of barriers imposed by the 6 month limit of the hospice benefit	4.73
9	Access to palliative care benefit from the time of diagnosis w/out a time constraint	4.55
10	Honesty	4.55

Based on the Five Cluster
Solution, A Basic Model of
Children's Needs Might Look
Like...

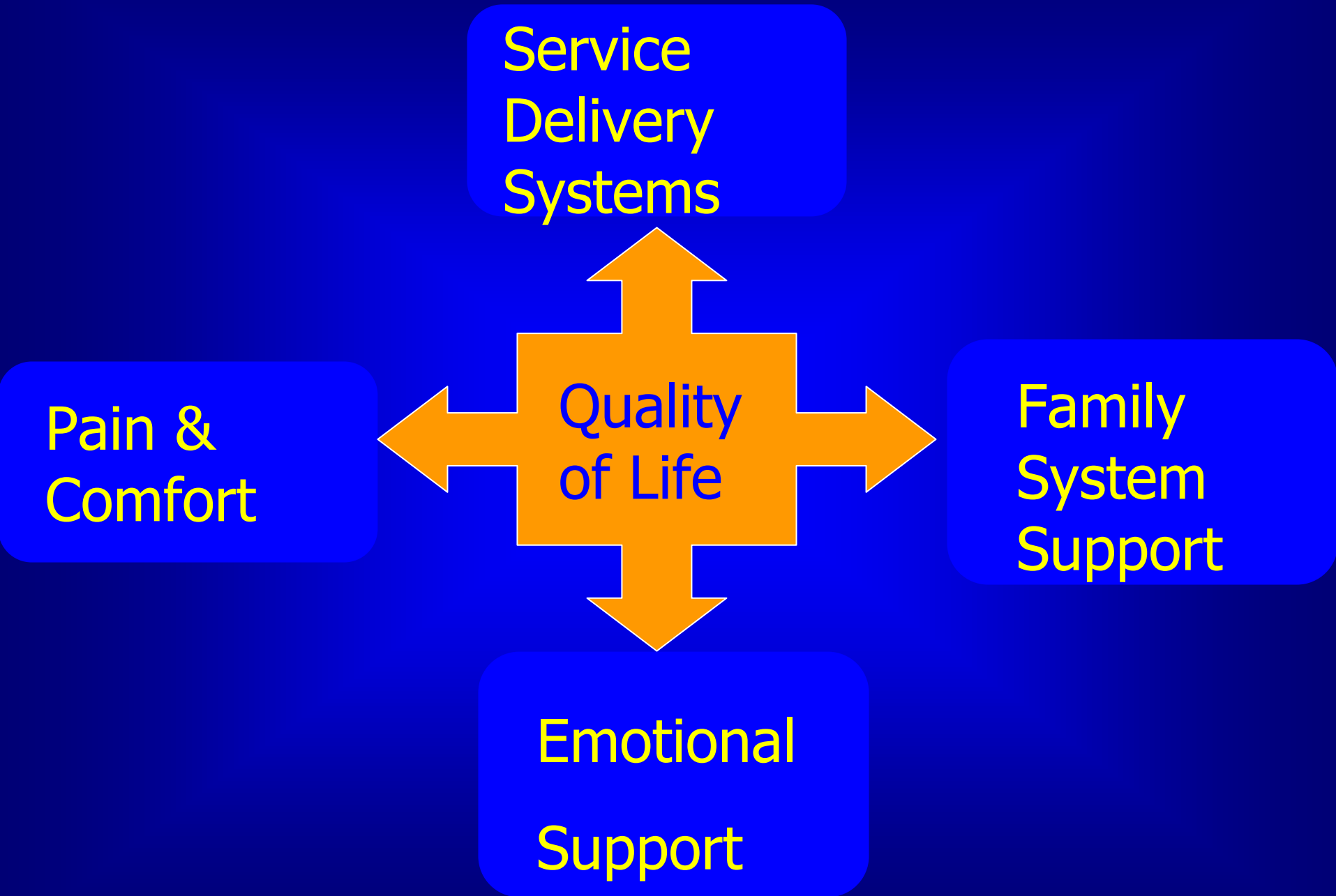
Service
Delivery
Systems

Pain &
Comfort

Quality
of Life

Family
System
Support

Emotional
Support



Summary

- A five cluster model appears to describe the set of 74 unique needs of the child.
- The model must be validated by feedback from families as well as experts in other locations.
- Assessment of specific needs should enable better treatment planning and evaluation of programs.