Palliative Care Medical Home:

Lessons from a Pediatric Palliative Care Practice Serving as a Medical Home for Children with Complex Chronic Conditions

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Greehey Distinguished Chair of Palliative Care for Children
University of Texas Distinguished Teaching Professor
Professor, Department of Pediatrics

December 8, 2016

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- **Webinar:**
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    Thursday, January 12, 2016 at 1:30 pm ET
    Featured Presenter: Barbara Sutton, APN, ACHPN

- **Virtual Office Hours:**
  - **Billing for Community-Based Palliative Care with Anne Monroe, MHA**
    - Monday, December 12 at 12 p.m.ET
  - **Ask a Program Leader (Open Topics) with Andrew Esch, MD, MBA**
    - Monday, December 12 at 2 p.m.ET
  - **Planning for Community-Based Palliative Care with Jeanne Twohig, MPA**
    - Wednesday, December 13 at 11 a.m. ET
  - **Building Effective Payer-Provider Partnerships with Tom Gualtieri-Reed, MBA and Kristofer Smith, MD, MPP**
    - Wednesday, December 13 at 1 p.m. ET

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Faculty Disclosure

- In the past 12 months, I have no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.
- I do not intend to discuss an unapproved or investigative use of a commercial product/device in our presentation.

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Learning Objectives

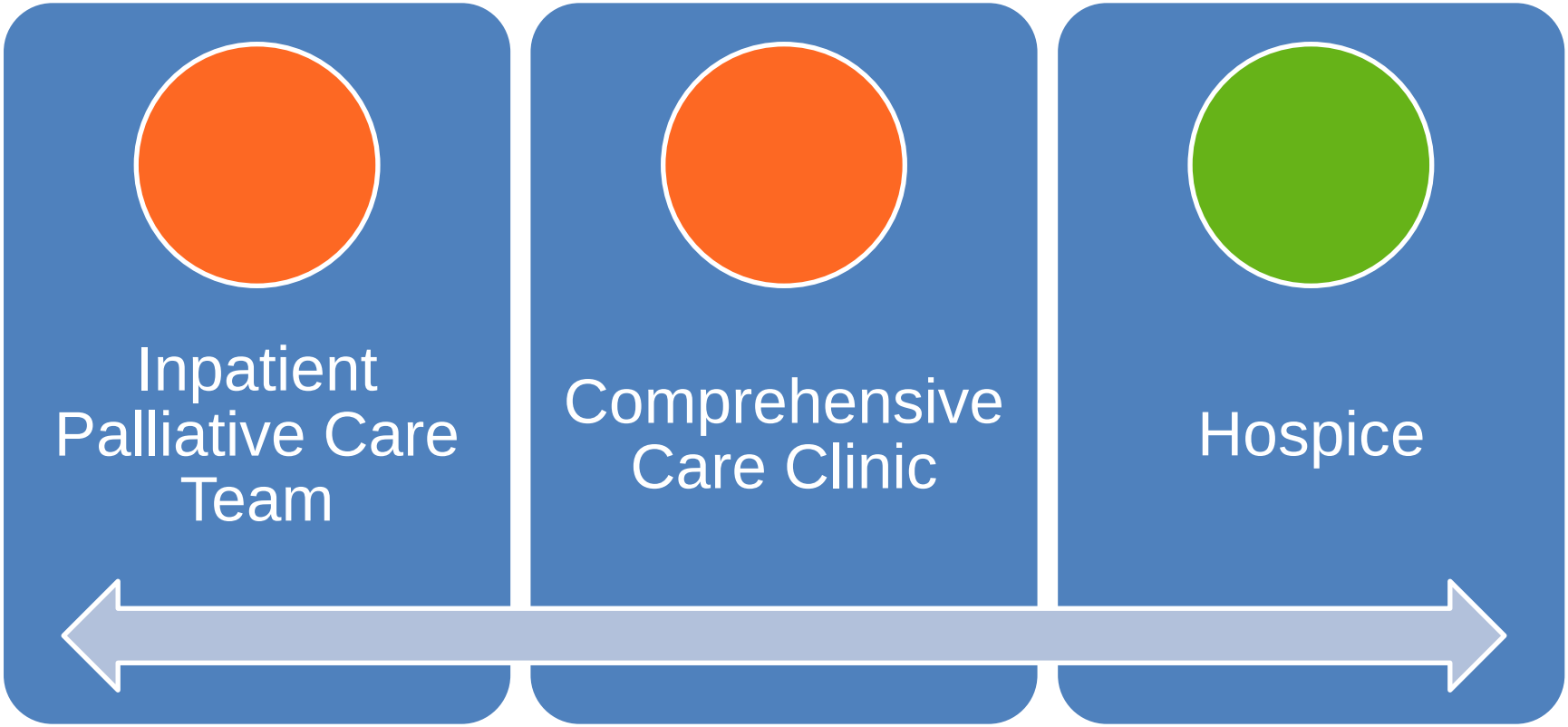
At the conclusion of this webinar, the learner will be able to:

1. Describe a medical home model that provides primary care for children with palliative needs
2. Identify key service capabilities needed for a successful medical home approach
3. Describe benefits of a reliable medical home approach for patients and families
4. Identify strategies for working with primary care practices to help them manage patients, while improving identification of patients appropriate for more focused management
5. Identify 2 financial justifications for investment in medical home design for palliative care patients

Comprehensive Care Clinic

- Outpatient service started in 2008
- Medical home for children with palliative care needs and medical complexity
- Inpatient palliative care team started in 2015
- Inpatient team with average daily census of 12 patients
- Children's Hospital within County Health System

Wrap-around Palliative Care Services



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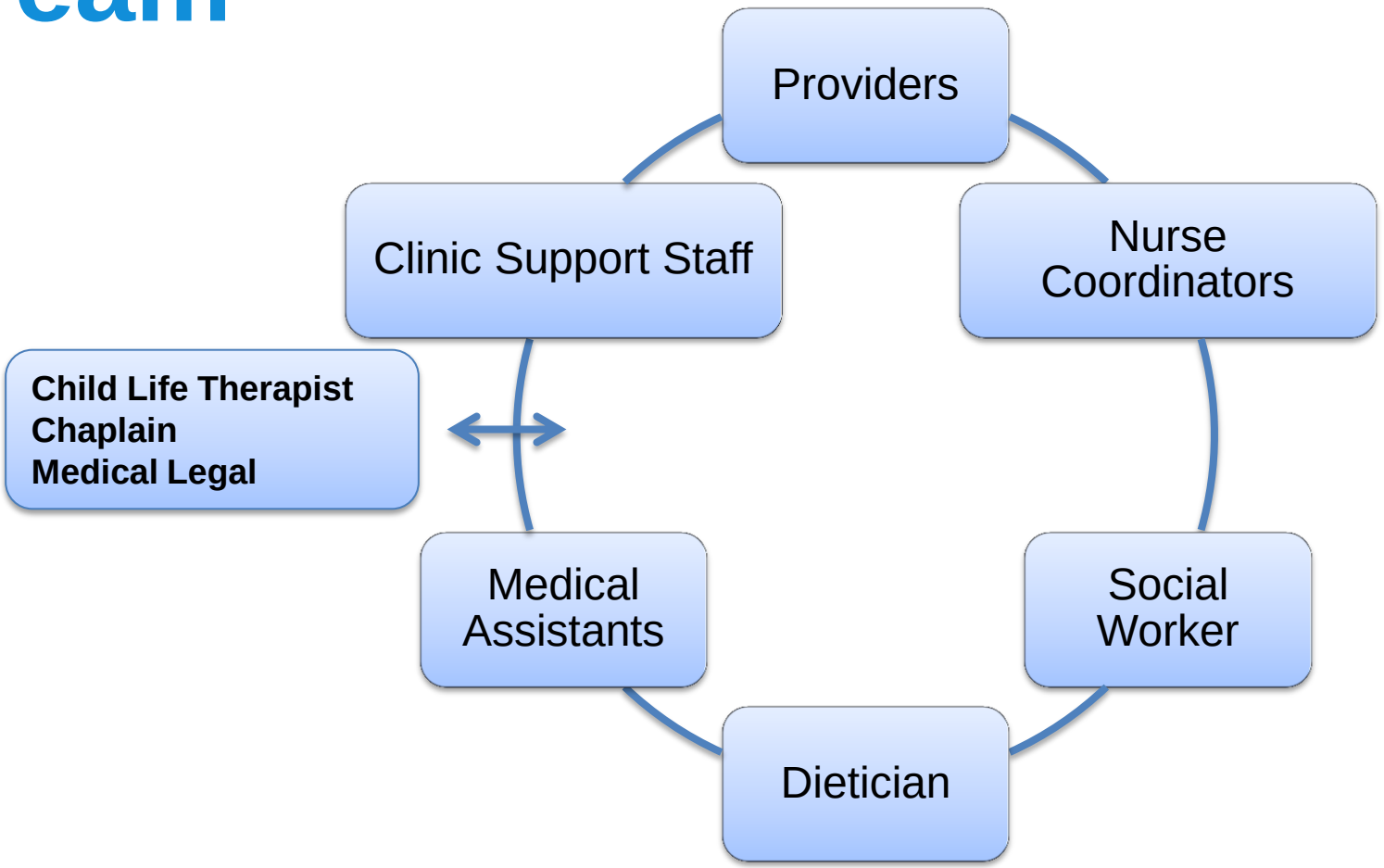
Comprehensive Care Clinic Team



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BACKGROUND LITERATURE

Palliative children live a long time

- Utah
- Patients who received inpatient PPC
- Follow-up:
  - 26% died within 10 days of discharge
  - 24% died between 10 and 730 days
  - 50% survived to 730 days after discharge

Smith AG, Andrews S, Bratton SL, Sheetz J, Feudtner C, Zhong W, Maloney CG. Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study. Pediatrics 2015;135(4):694-700.

Children spend most of their last year of life at home

Diagnosis	Hospital Days Last Year Life
Neuromuscular	24
Cardiovascular	29
Congenital / Genetic	31
Malignancy	51
>3 LT-CCC	75

Smith AG, Andrews S, Bratton SL, Sheetz J, Feudtner C, Zhong W, Maloney CG. Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study. Pediatrics 2015;135(4):694-700.

Hospital care is expensive

EXHIBIT 1

Health Care Use And Spending For Children With Medical Complexity And Medicaid, By Health Service, 2011

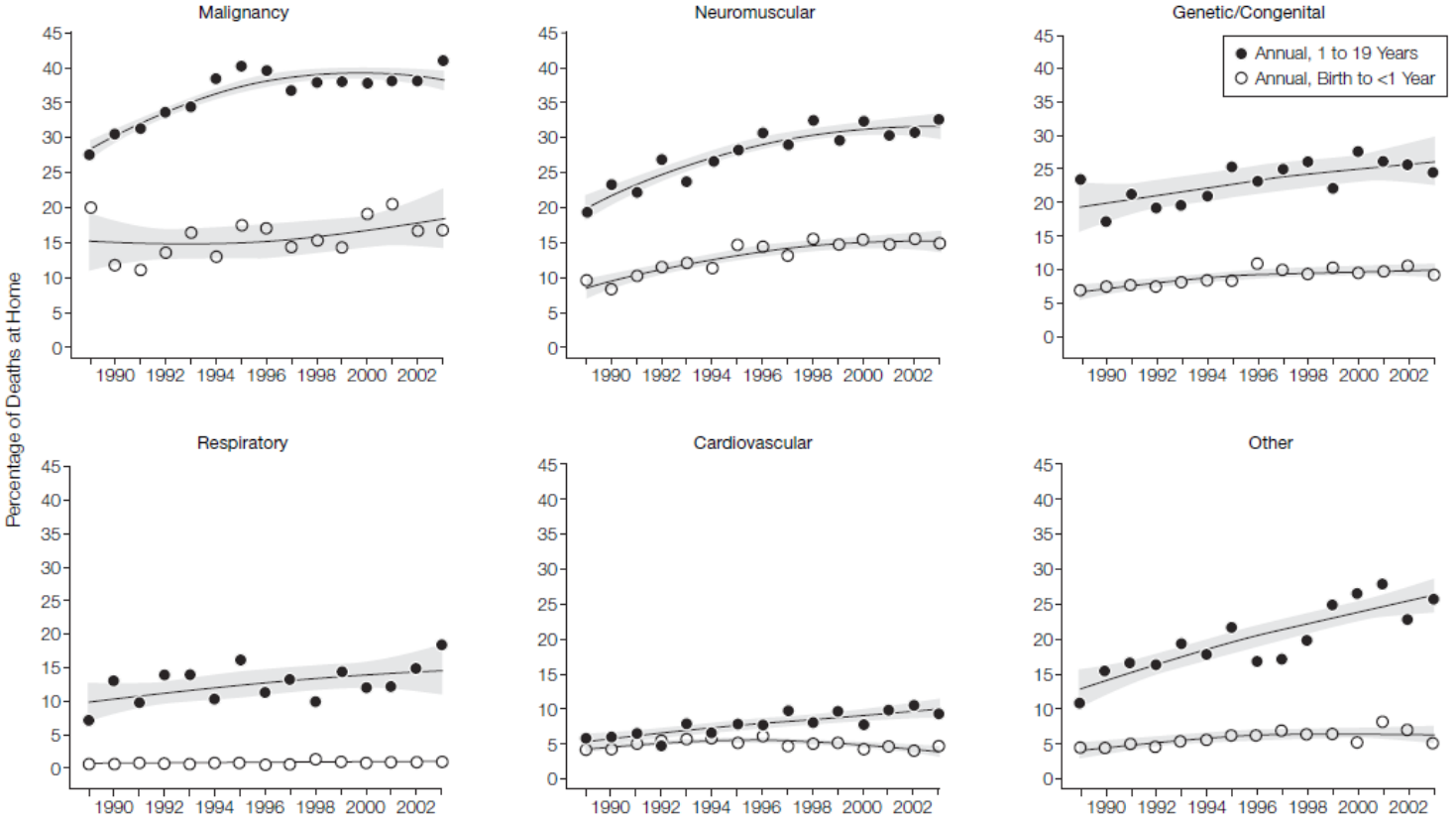
Health service	Percent of children using the health service	Annual spending per child ($)	Percent of health care spending for children with medical complexity
Hospital care	13.0	5,903	47.2
Outpatient specialty and other care	66.0	3,136	25.1
Medications	89.9	1,677	13.4
Outpatient therapy	22.4	593	4.7
Emergency care	32.3	383	3.1
Primary care	59.6	275	2.2
Laboratory and radiographic testing	54.9	230	1.8
Home health care	3.2	204	1.6
Medical equipment and supplies	16.7	98	0.8

SOURCE Authors' analysis of 2011 data from the Truven Marketscan Medicaid Database.

Berry JG, Hall M, Neff J, Goodman D, Cohen E, Agrawal R, Kuo D, Feudtner C. Children with medical complexity and Medicaid: spending and cost savings. Health affairs (Project Hope) 2014;33(12):2199-2206.

Many children die at home

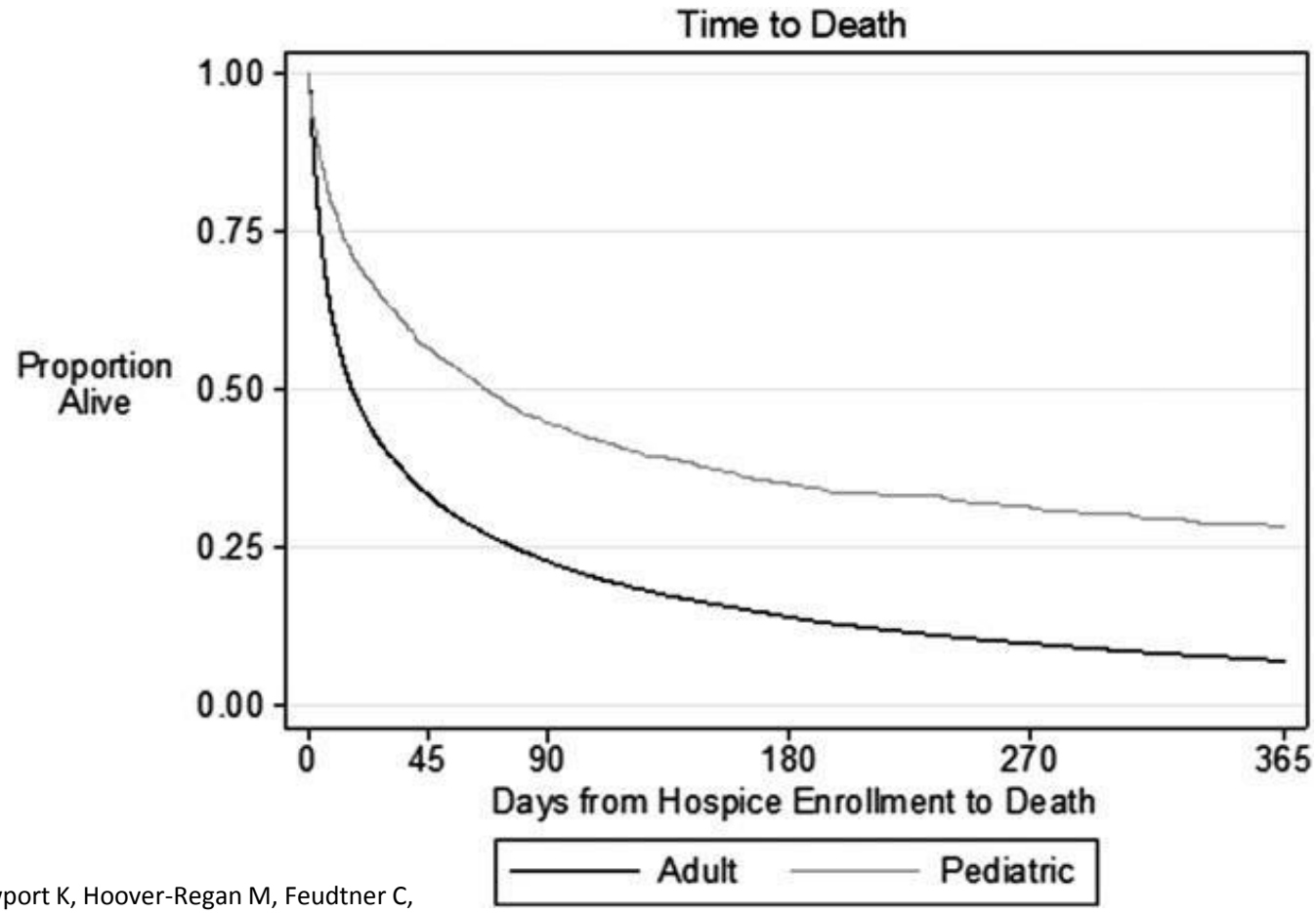
Figure 3. Percentage of Deaths Occurring at Home by Predominant Types of Complex Chronic Conditions, 1989-2003



The dots represent the percentage of deaths that occurred at home each year. The curved lines represent the temporal trend in the percentage of deaths that occurred at home as estimated by the best fitting fractional polynomial model, which also estimated the 95% confidence intervals indicated by the shaded areas.

(Reprinted) JAMA, June 27, 2007—Vol 297, No. 24 2729

Children with terminal diagnoses live a long time



Dingfield L, Bender L, Harris P, Newport K, Hoover-Regan M, Feudtner C, Clifford S, Casarett D. Comparison of pediatric and adult hospice patients using electronic medical record data from nine hospices in the United States, 2008-2012. Journal of palliative medicine 2015;18(2):120-126.

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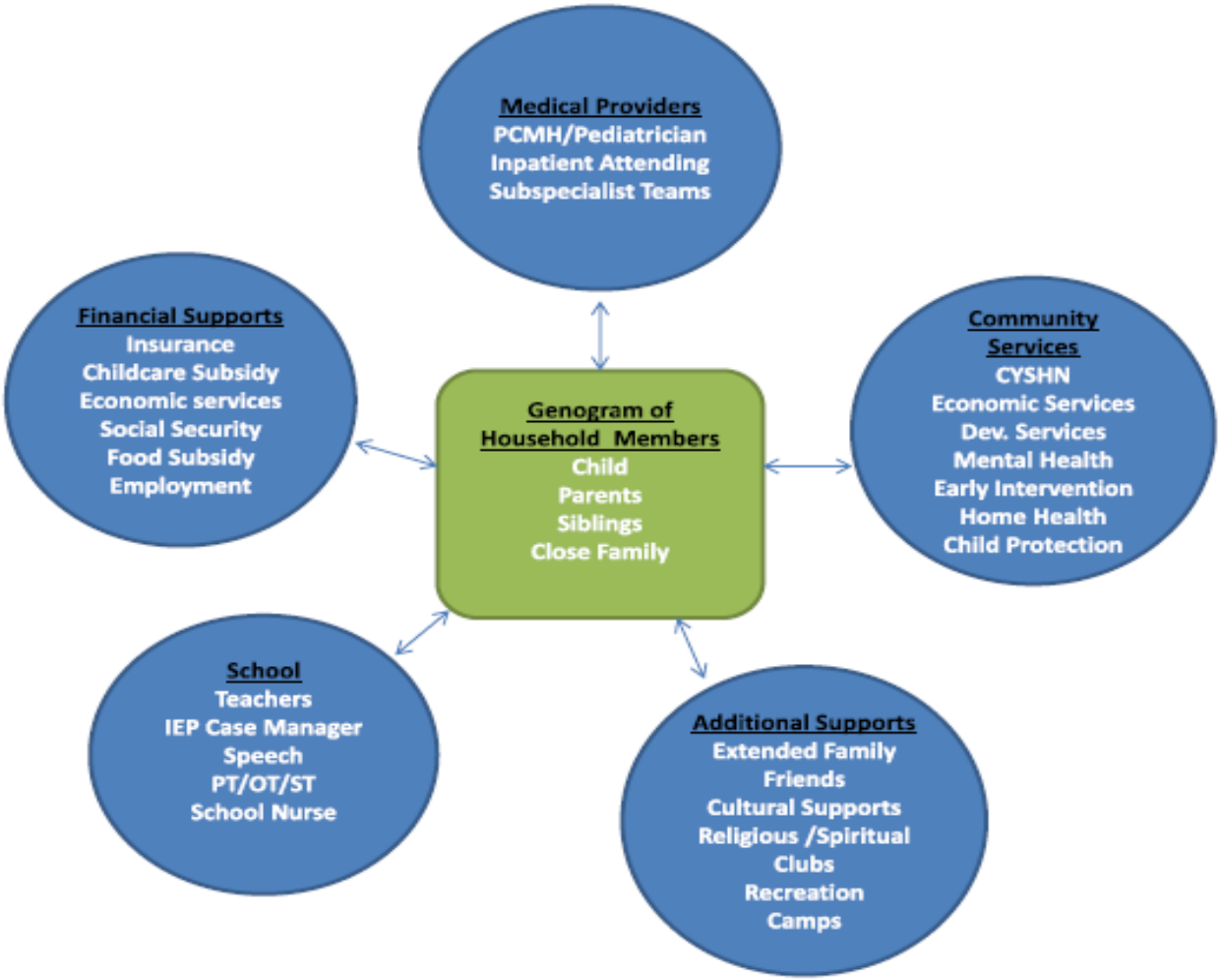
How palliative care teams interface with outpatient services

	#	%
Relationship with 1 or more hospices	81	80.2
Health system has own hospice	13	12.9
Palliative care and hospice function together	7	6.9
Home Visits	33	29.5
Outpatient clinic	21	18.8
Patients seen in other clinics	67	59.8
Outpatient phone support	68	60.7
Home-based palliative care	12	10.7
No outpatient services	24	21.4

Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. Pediatrics 2013;132(6):1063-1070.

Outpatient care is complex



Ogelby M, Goldstein RD. Interdisciplinary care: using your team. Pediatric clinics of North America 2014;61(4):823-834.

San Antonio Experience

- Selecting patients for the clinic
- Stratifying complexity and needs

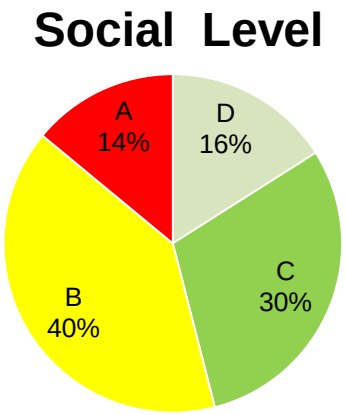
Medical Criteria 1. Hospice, DNR, or life-limiting illness with death probable during childhood 2. Chronic illness with 3 or more organ systems involved requiring subspecialty support 3. Technology dependence of 2 or more organ systems 4. Complex pain and symptom management	Examples: • Tay Sachs, adrenoleukodystrophy • Tracheostomy, home ventilator and gastrostomy • Traumatic brain injury with gastrostomy and spasticity • Hypoplastic left heart • Chronic pancreatitis
Financial Criteria Chronic illness impacting ADL and: 1. 3 or more ED visits in 6 months 2. 2 or more admissions in 6 months 3. Identification by Hospital Administration	Examples: • Short gut with recurrent line infections • Renal insufficiency with prolonged hospitalizations • ECMO with residual impairment
Social Criteria Chronic illness impacting ADL and: 1. Inability to be supported in current UHS primary or subspecialty clinic due to medical illiteracy or family psychosocial limitations 2. Foster care 3. Child Protective Services	Examples: • Cerebral palsy removed by CPS in medical foster home • Brain tumor with family having difficulty coordinating care

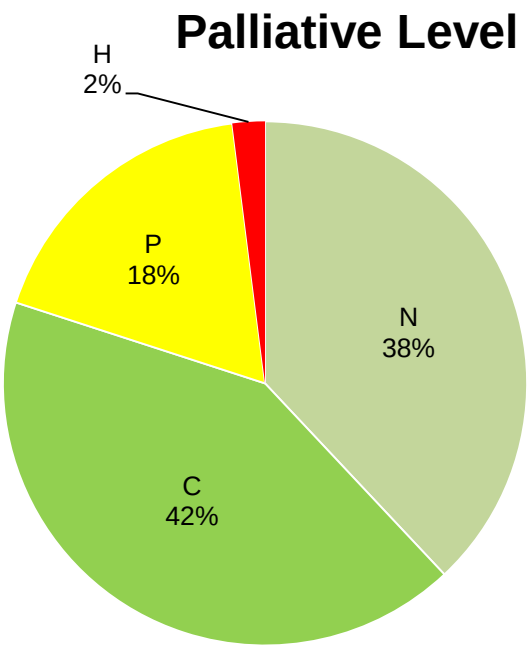
Risk category	Medical		
	Healthcare utilization (in last 6 months)	**Medical complexity**	**Functional**
Minimal risk (Level 4)	- No ED visits - No inpatient hospitalization	No chronic medical conditions	Appropriate motor, speech, feeding functions
Low risk (Level 3)	- 1 ED visits for emergent needs - 2 sick visits	- 1 active chronic diagnoses, well controlled - Less than 5 medications	Assistance in 1 domain of motor, speech or feeding
Moderate risk (Level 2)	- 2 ED visits for emergent - 1 ED visit for non-emergent - 1 inpatient hospitalization - 3 sick visits - 4+ specialists visits	- 2 active chronic diagnoses or 3 chronic diagnoses well controlled - - 5 to 9 medications	Wheelchair dependent, home nursing
High risk (Level 1)	- More than 2 ED visits for emergent or non-emergent needs - 2+ inpatient hospitalizations - 1 prolonged hospitalization *(>2 weeks)* - Subspecialty management requiring CCC coordination	- 10+ medications - 3+ active chronic diagnoses - Complex pain and symptom management - Life-threatening illness	Bed-bound or restricted to home

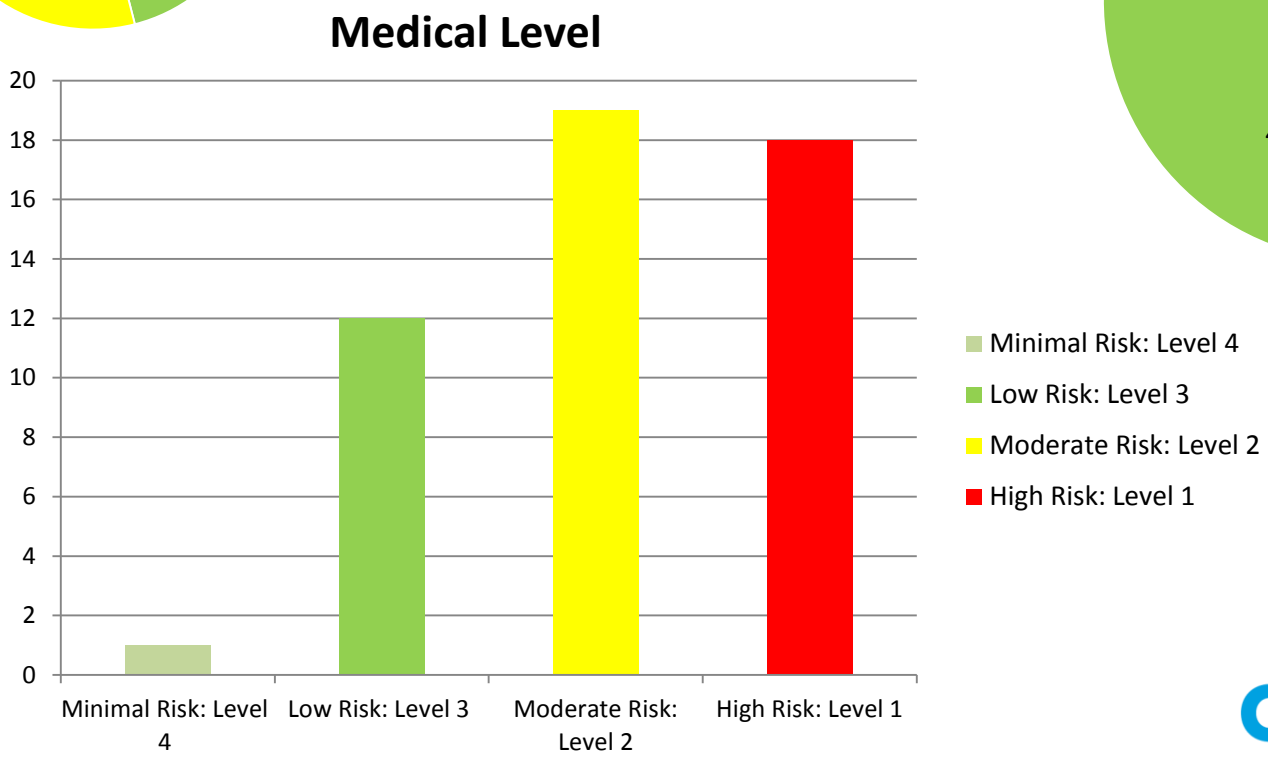
Risk category	Social
D	- Compliant with appointments - No social concerns
C	- Few missed appointments - Needs assistance to follow medical plan - No social concerns
B	- Multiple missed appointments - Needs social or coordination assistance at least monthly - Social concerns
A	- Many missed appointments - Intense coordination needs - Intense social worker support - CPS involvement

Risk category	Palliative
N	- Stable illness
C	- Complex chronic illness, life-altering but not life-threatening
P	- Palliative - Life-threatening but not actively dying - Complex pain and symptom management
H	- Hospice - Hospice-qualifiable - OOH DNR

Most Recent 50 Clinic Visits







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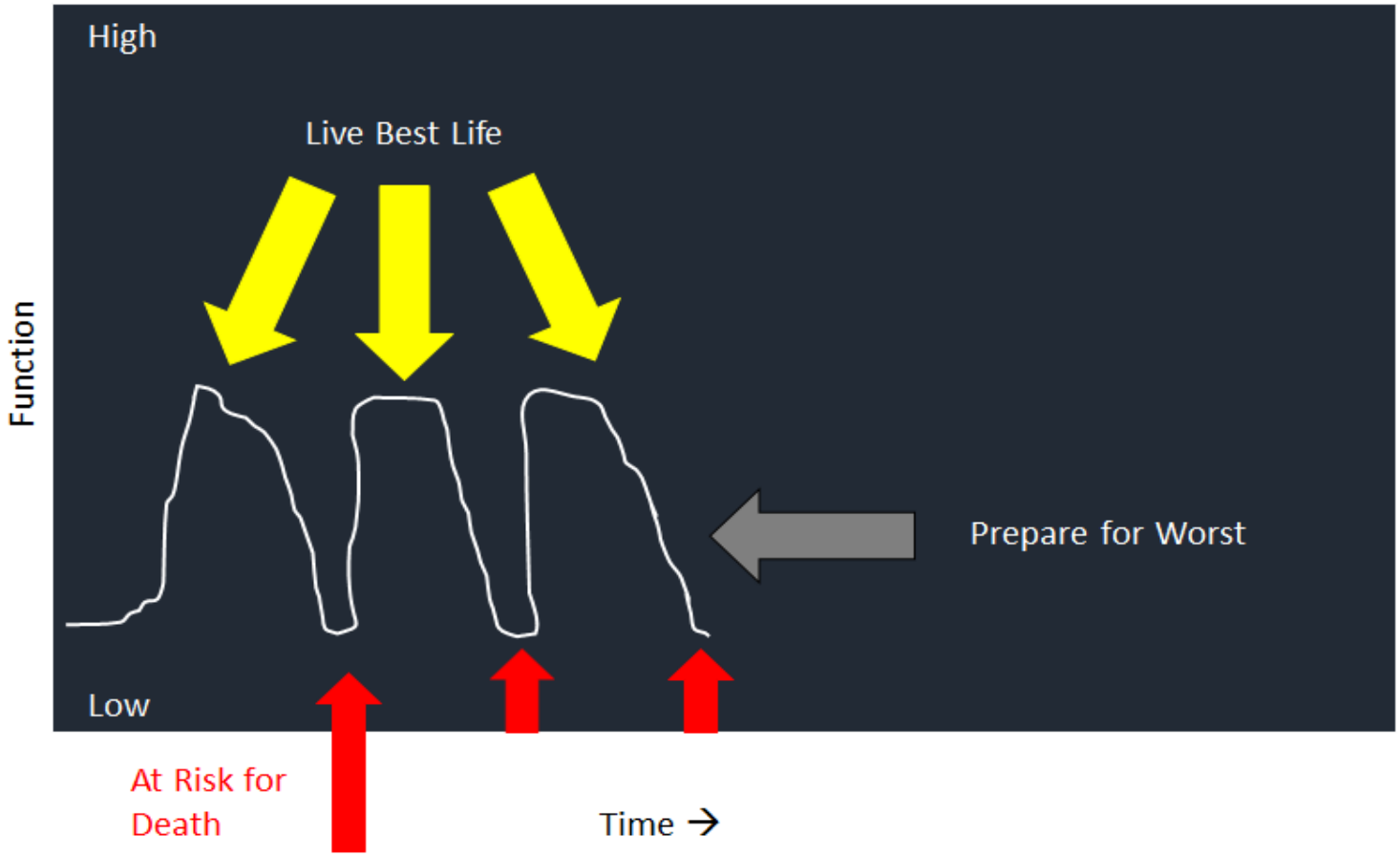
Staffing

- Per 1.5 FTE Provider (9 clinic sessions per week)
  - 2 Nurse Coordinators
  - 2 medical Assistants
  - 1 Social Worker
  - 1 Dietician
- Access to
  - Chaplain
  - Child Life Therapist
- Clinical Operations

Inpatient vs. Outpatient Illness Experience



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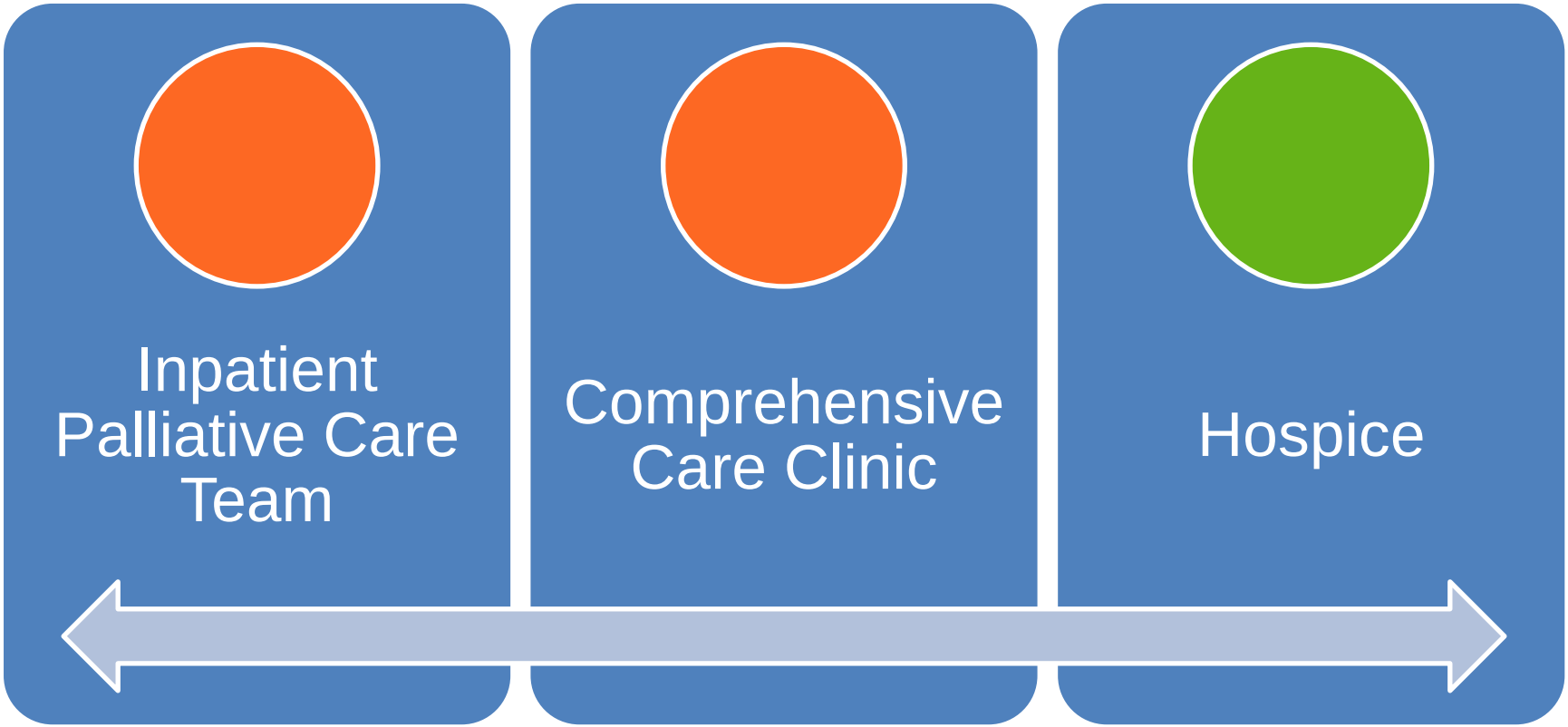
Comprehensive Care Clinic 2015

- 359 enrolled children
- 2,338 visits
- Average 4.3 visits per patient per year
- Death rate 4.3:100 patients per year
- 4.8% enrolled in concurrent hospice

Children who died in CCC panel

- Median age 6 years
- Median time on service 11 months
- Enrolled in hospice 30.7%
- Died at home 71.8%
- Died suddenly 56.4%

24/7 Coverage



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Financials for clinic operations

- Salary for dedicated staff $443,445
- Supplies $12,801
- Hospital-based clinic revenue about 30% costs
- Average PMPY $13,013

Need Arguments

- ➔ Patients
- ➔ Specialists
- ➔ Hospitalists
- ➔ Neonatologists

Stratifying expensive patients

- 315 patients
- 15 patients incurred > $3M direct costs to healthcare system
- Other 300 patients incurred an additional $3M direct costs

Financial Arguments

- Cost avoidance is the best argument.
- These children are expensive – high risk group.
- Cohorting these children can initially look prohibitively expensive.
- We need to use different arguments than adult palliative care – cost savings is hard to show.

Medicaid Funding

- 1915(c) Pediatric palliative Care Waivers
  - California
  - Colorado
  - North Dakota
- 1915 (c) Medically Fragile Children Waivers
  - New York

Medicaid Funding

- 1915(b) Waiver
  - Florida
- EPSDT State Plan Amendment
  - Washington
- State Funded
  - Massachusetts

How: Funding Looking Forward

- Medicaid Managed Care Organizations (MCO)
  - Per patient per month
  - Funding recognition for being a center of excellence
  - Payments for telephone management, care coordination
  - Exploring Tele-health
- Accountable Care Organization (ACO)
  - High risk group

Transitions

- Improvements in medical care and technology have increased the likelihood that CSHCN will live to adulthood.
- Patients and families are comfortable with their pediatric medical services and are hesitant to begin the transition to adult care.

Transitions

- 90% of children with chronic health care conditions survive to adulthood
- 500,000 youth with special health care needs reach the age of 18 every year
- AYA – Adolescent and Young Adult

Secondary Palliative Care

- Provided by specialist palliative clinicians that provide consultative and specialty care.

Primary Palliative Care

- Care provided by all clinicians caring for a patient with serious illness
- Requires basic clinical skills that should be required of all clinicians
- Education at all levels of clinical care needed to allow effective care to be provided

Structural barriers

-Time constraints, too many patients-too little time

Knowledge barriers

-Limited HPM education during training, limited time for CME

Service barriers

-Limited reimbursement for time intensive service

Lessons Learned

- Pediatric palliative care is often delivered over years.
- A coordinated approach makes being on-call very doable.
- Splitting inpatient and outpatient workflows decreases stress of teams.
- Palliative care doctors must partner with Complex Care and Primary Care Pediatricians.

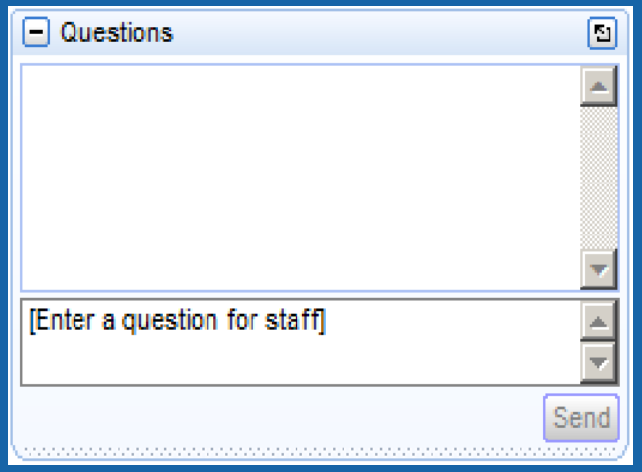
Where do we go from here?

- ➔ Expansion CCC without overwhelming clinic.
- ➔ Increasing ability of other pediatric clinics in system to take care of less complex patients.
- ➔ Hiring providers that like medical complexity, but are not HPM trained.
- ➔ Contracting with MCO.
- ➔ Telehealth

Questions?

Do you have questions for the presenter?

Type your question into the chat box on your control panel:



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