Children with Chronic Illness: A Focus on Home Management Issues

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Children with Medical Complexity

- Intensive hospital- and/or community-based need,
- Reliance on technology, use of multiple medications and/or assisted care to maintain a basic quality of life
- Risk of frequent and prolonged hospitalizations that leads to high health-resource utilization,
- Elevated need for care coordination.

Example Populations of CMC

- Cancer
- Cystic Fibrosis
- AIDS
- Congenital Anomalies
- Neurodegenerative Diseases
- Metabolic Disorders
- End-stage organ failure
- Neurological Impairment/Trauma

Health Care Expenditure

- Although CMC represent only 1.0-1.5% of the total pediatric population, the costs of their care represent 30% of the care for the overall pediatric population.
- Approximately 70% of CMC are insured through Medicaid as a primary payer, with even more using Medicaid as a secondary payer.

Impact of CMC on Family

- Social Isolation
- Financial burden
- Family interpersonal stress
- Parenting
- Siblings

Unmet Needs

- Informational Needs
- Access to subspecialty and community services
- Care Coordination
- Social Support

Implications for Program Development

- Family Centered
- Community Based
- Access to continuum of care

Implications for Program Development

- Flexibility to serve wide range of CMC
  - Perinatal care
  - Transition from pediatric to adult services
  - End-of-life care
  - Bereavement

Models

- Specific to sub-population
  - Malignancy
  - Pulmonary
  - Spina bifida
  - Muscular dystrophy
- Rare diseases
  - Menke's Disease
  - Spinal Muscle Atrophy

Viable Models of Care

- Medical Home
- Case Management
- Patient Navigator

The Medical Home

- Key Components
  - Accessible
  - Continuous
  - Comprehensive
  - Family Centered
  - Coordinated
  - Compassionate
  - Culturally Effective

The Medical Home

- Status of Care Coordination
  - 71% of physicians surveyed reported that they or someone in their office functioned as primary care coordinator for CSHCN
  - HOWEVER
    - 23% contacted school re child's health issues
    - 18.7% scheduled time with family to discuss findings of specialist
    - 23% met with discharge planning staff to facilitate transition from hospital to home
  - Primary barriers – lack of time, resources, training

Gupta, O'Connor, Quezada-Gomez, Pediatrics, 2004

Case Management

- Case Management
  - Cost Containment
  - Utilization Review/Care Authorization
  - Referral Resource
  - Discharge Planning
- Not necessarily tied into medical plan of care

Home Care

- Intermittent acute care nursing visits
- Private duty nursing care
  - Medicaid (Comprehensive Care Program)
  - Medically Dependent Children's Program
  - Consolidated Waiver Program
- Home Based Therapies

Hospice

- Community based program that uses an interdisciplinary team of health care professionals to provide comprehensive palliative care for terminally ill patients and their families

- Significant limitations for pediatric population

Lay Parent Navigators

- Work with family and health care team to develop a care plan.
- Work with families to arrange travel to /from the hospital.
- Monitor family functioning through phone, email, social media, and home visits to prevent or mitigate health care crises.
- Assist families in working with durable medical equipment providers and home care nursing services.
- Ensure information sharing and care coordination with school, community, and home care agencies/resources.
- Advocate for families in the health care system.

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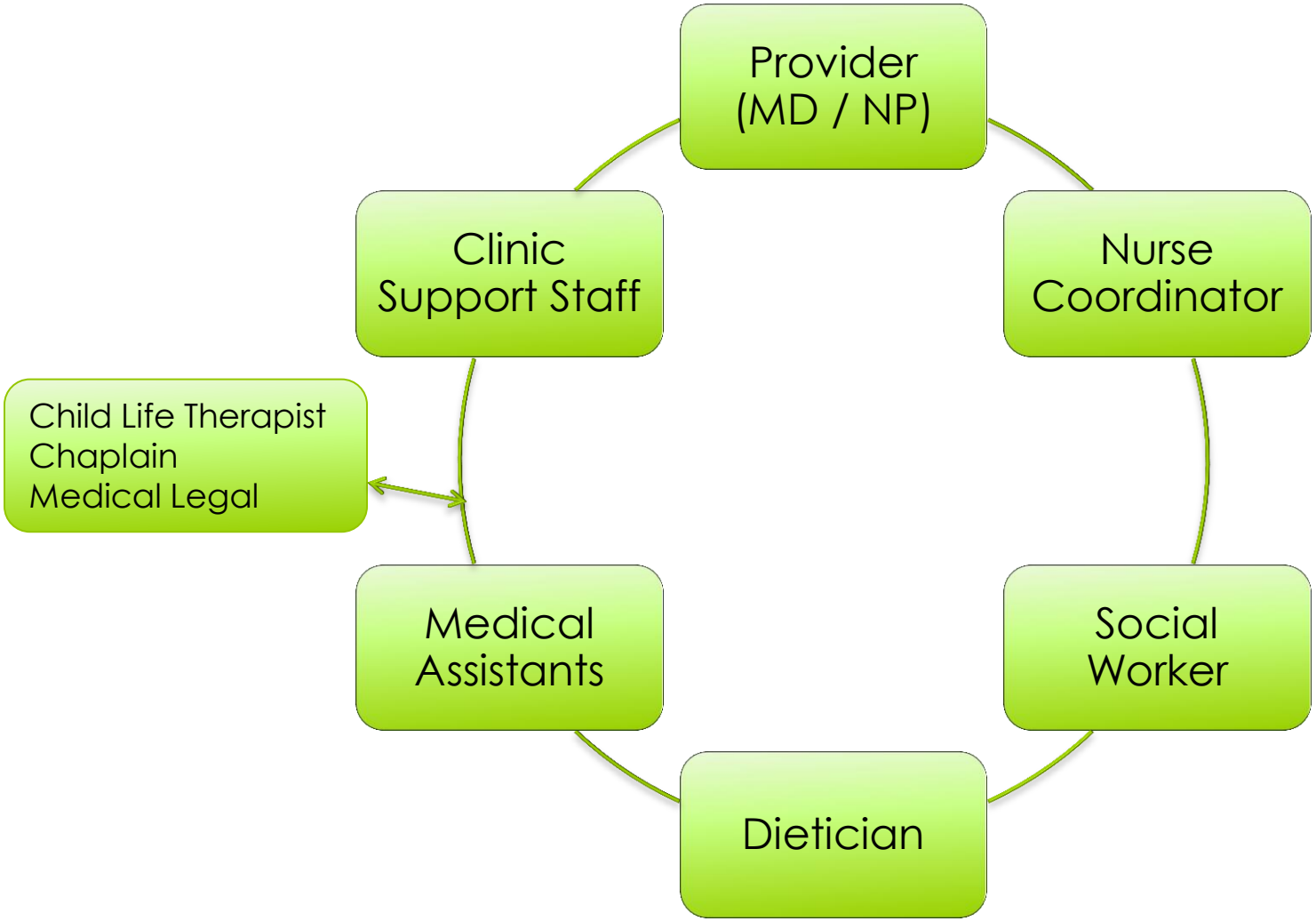
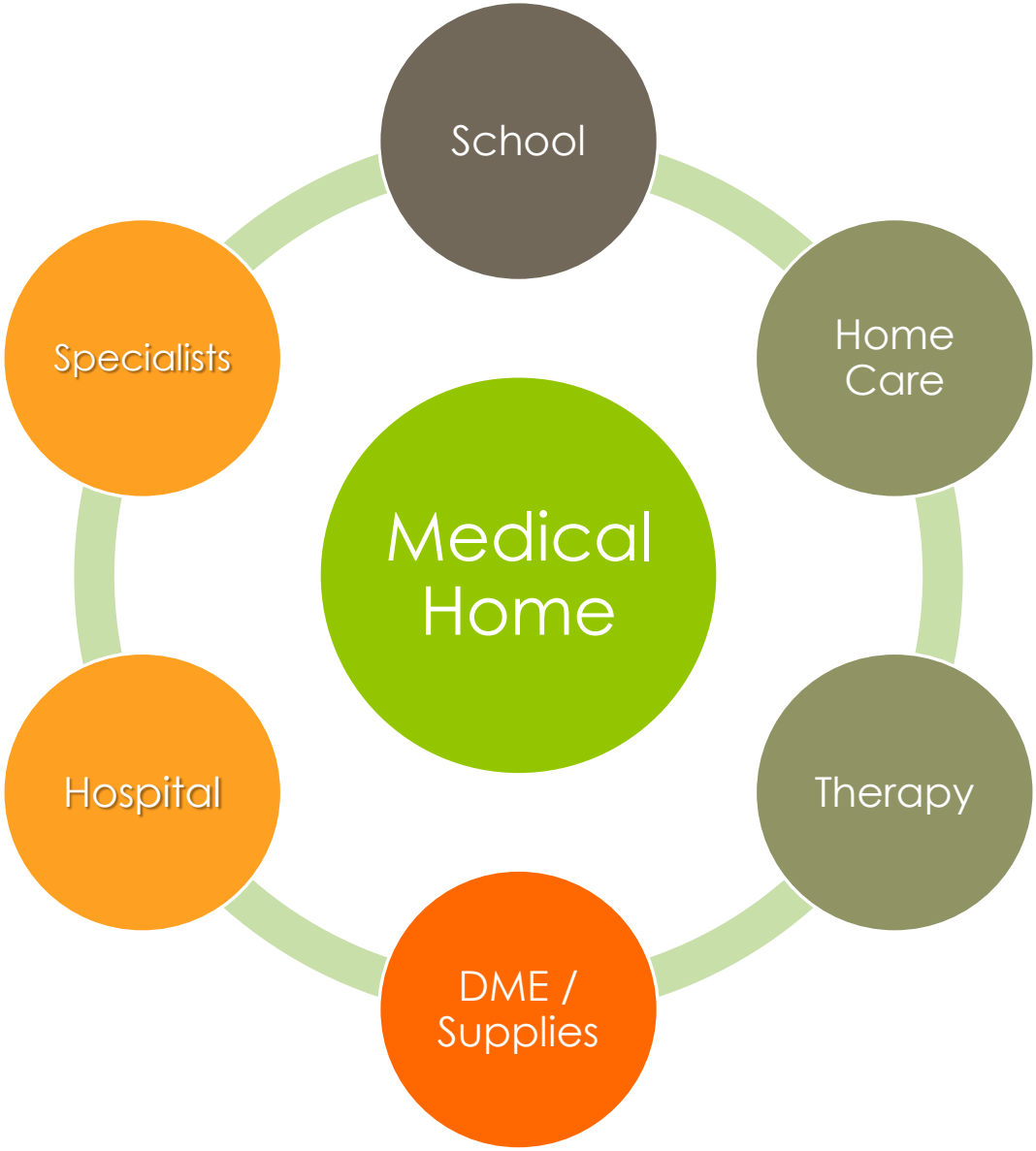
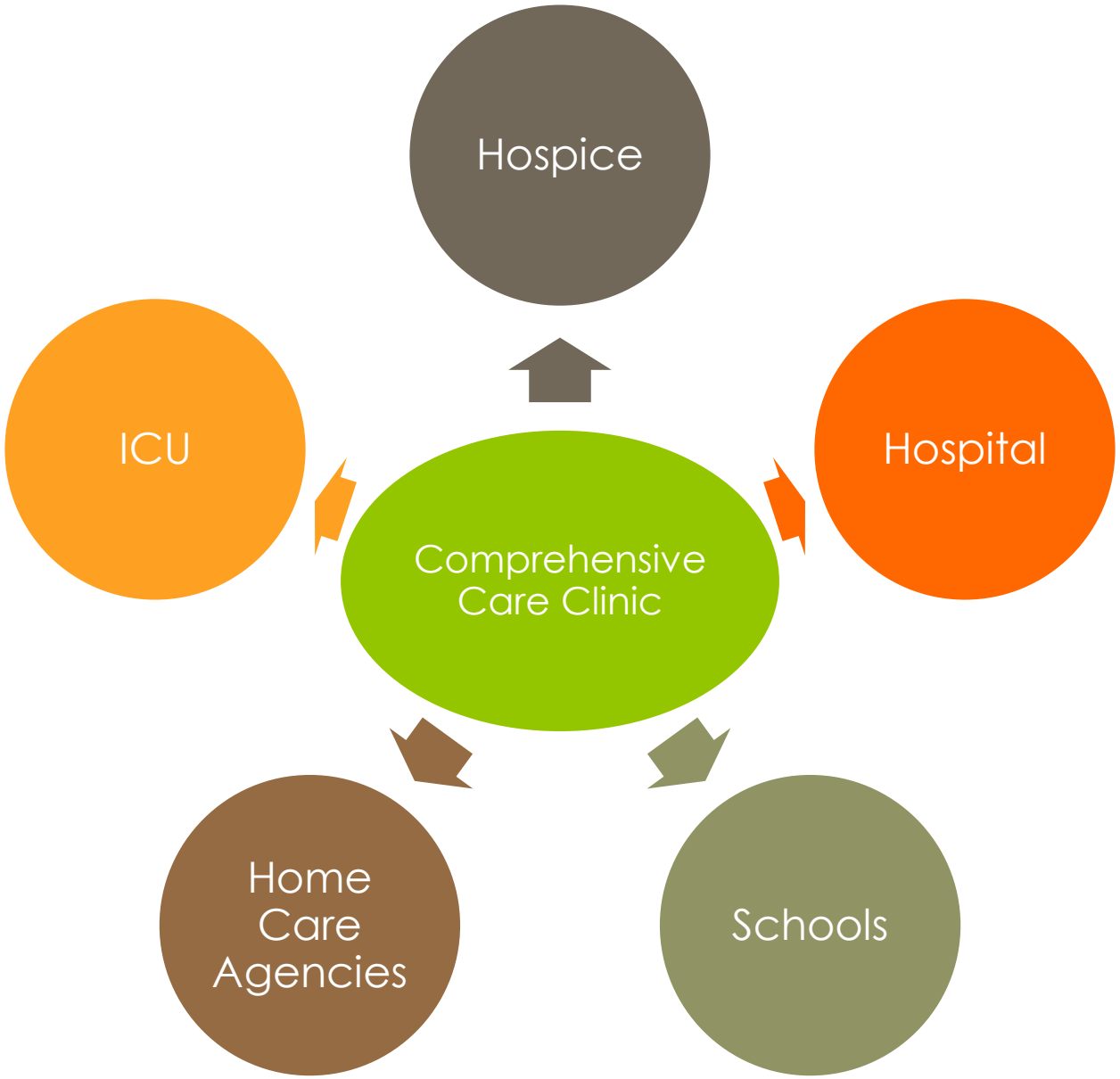
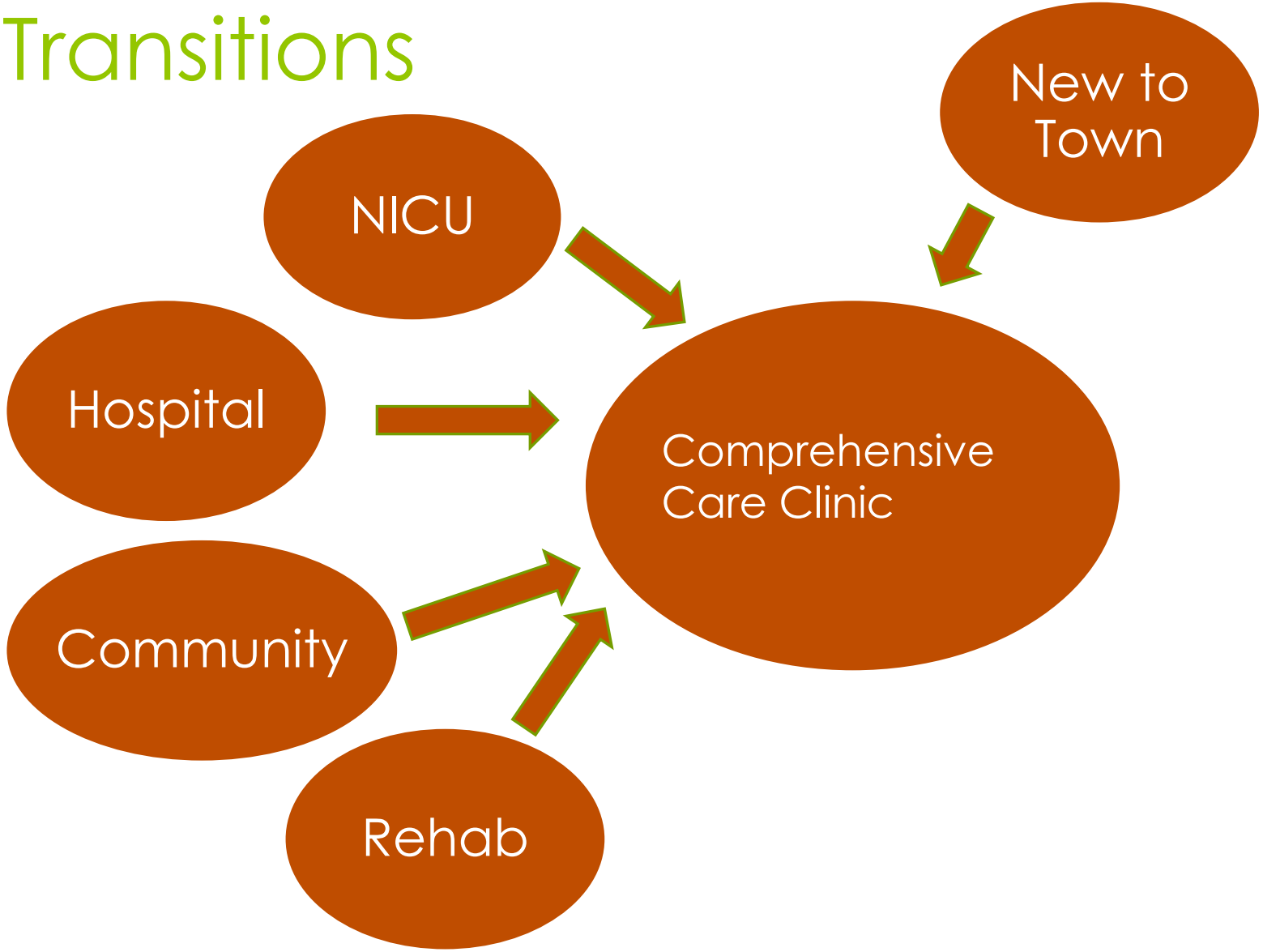
Comprehensive Care Team




School
Home Care
Therapy
DME / Supplies
Hospital
Specialists
Medical Home


Hospice
ICU
Hospital
Comprehensive Care Clinic
Home Care Agencies
Schools

Transitions



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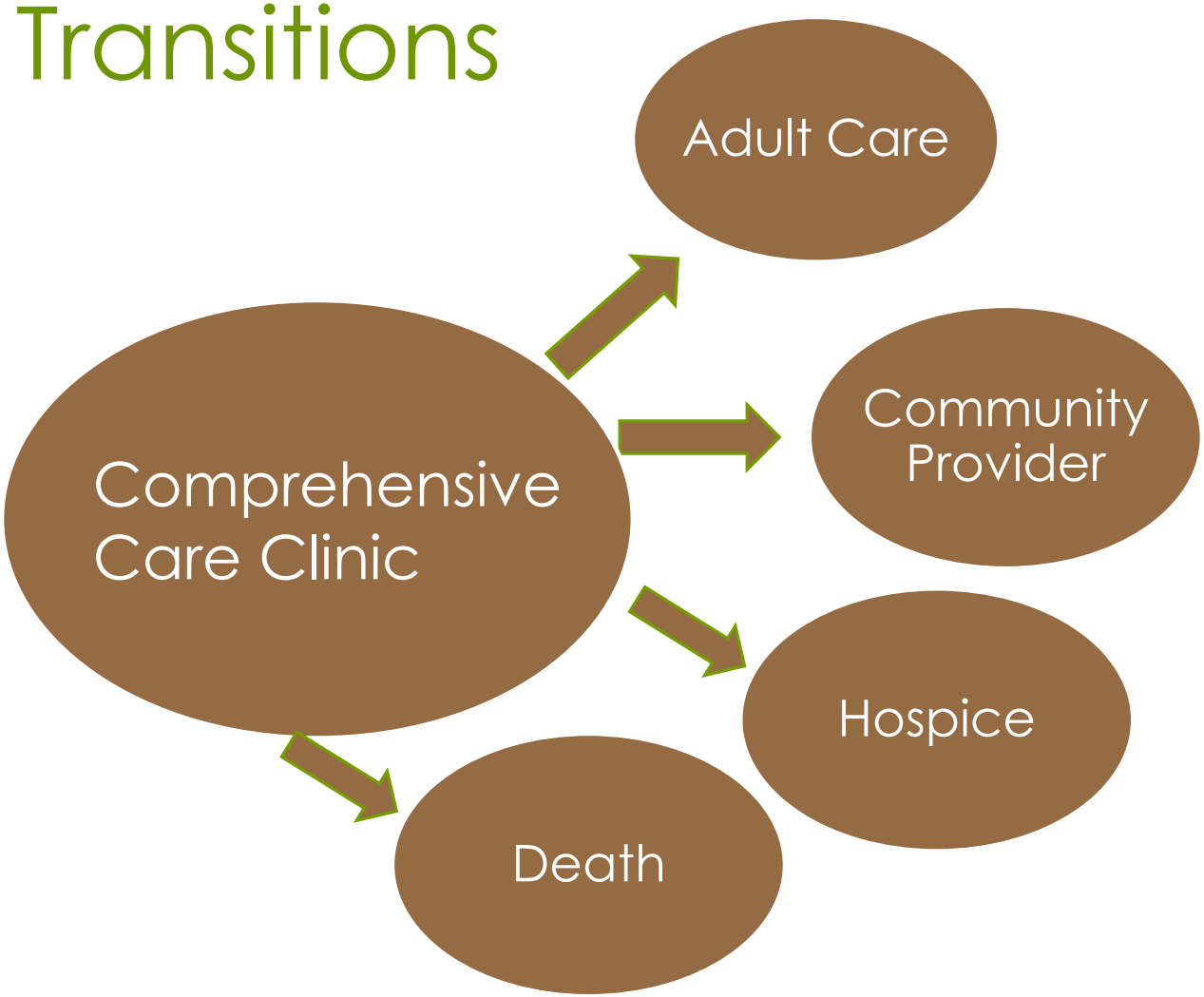

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Some clinic metrics

- 320 children with complex chronic conditions
- 67% with gastrostomy
- 25% with tracheostomy
- 17% home ventilator (excluding bipap)
- 52% home nursing
- Average 9 visits per year
- 5% mortality rate

Additional cost

- Salaries: About $200,000 per year
  - $675 per patient per year
- Decreased provider productivity
- Increased space utilization
- High volume of calls

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"Expensive" model

- Billing covers about 1/3 cost of operating clinic
- Subsidized by
  - County health system
  - Department of Pediatrics
  - Grant funding
  - Philanthropic
- Currently sustainable, but not expandable.

Financial Data

- ✓ Comparing stays from 2006 to 2009:
- ✓ Reduction on the patient length-of-stay by 41%
- ✓ Decrease on the Case-Mix-Index from 2.25 to 1.5 (lower than budget for the region)
- ✓ 9% decrease overall in the average cost per inpatient case

- ➢ A savings of almost $300,000 for 100 patients

Paperwork