Pediatric Long-term Care

Children with Severe Neurodevelopmental Impairments

Medically Fragile?

Definition Dilemma

“I can’t define [it] but I know it when I see it.”

Justice Potter Stewart

Definition Dependent

- Chronically ill
- Seizures
- Respiratory illnesses
- Feeding disorders
- Mental retardation
- Disabilities
  - Congenital
  - Acquired
- Technology dependent
Medically Fragile Children
- Three or more chronic conditions
- Severe neurodevelopmental impairment
- Technology dependent

Scope of the Problem
- Definition dependent
- Estimated 101,000 children 0 – 17 years
- Doesn’t include
  - Subacute rehab
  - Acute rehab
  - Acquired problems

Types of Care
- Home Care
- Residential
  - Intermediate Care Facility - ICF
  - Individual Resident Alternative – IRA
  - OMRDD regulations
- Skilled Nursing Facility - SNF
  - 115 in US and Canada
  - DOH regulations

SNF Services
- Institutional based (congregate housing)
- Twenty-four hour nursing
- Occupational therapy
- Physical therapy
- Speech therapy

SNF Services
- Dietary services
- Respiratory therapy
- Pharmacy
- Social work
- Leisure and activities
- Respite care

SNF Medical Services
- Medication administration
- GT management
- Airway management
- IV infusions
- Advanced wound care
- Ventilator management
SNF Activities
- Not institutionalized or warehoused
- Attend school-based programs
- Attend a variety of “outings”
- Week-end home stays
- Family day trips

SNF Staffing
- Medical staff
  - MD
  - NP – general
  - NP – pulmonary
- Nursing
  - RN
  - LPN
  - Aides
  - Respiratory therapy

SNF Support Staff
- Social workers
- Occupational therapist
- Physical therapist
- Speech therapist
- Activities

SNF Patients
- Congenital diseases
- Severe anoxic brain injuries
- Traumatic brain injuries
- CPS holds
- Multiple technologies dependent
  - Ventilators
  - Feeding tubes
  - Difficult airway management

SNF Patients
- Most have families
  - Very devoted
  - Visit regularly
  - Assist in care
- Some have only SNF family

Goals of SNF Care
- Not to warehouse patients
- All patients have discharge plans
- Strengthen family care
  - Support
  - Education
  - Hands-on care
  - Maintain therapy guidelines
Pitfalls of SNF

- Reimbursements
  - Medical care
  - Nursing care
  - All other services provided by facility
- Too many “mothers”
- Behavioral issues
- School districts

Pitfalls of SNF

- Guardianship
  - Hospital care
  - End-of-life issues
  - Aging population

A Day in Long-term Care

- AM care/feeds
- Bus ride to school
  - All equipment
  - RN on bus
- School activities
- Bus ride home
- After school activities
- PM care/feeds

The Future

Site Plan

Entrance
Pediatric Unit

Floor Plan

Physical Therapy

Pediatric Long-term Care

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