

Pediatric Long-term Care

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Pediatric Long-term Care

- Definitions
- Scope of the Problem
- Types of Care
- Skilled Nursing Care
- The Future

Long-term Care for the Medically Fragile Child 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



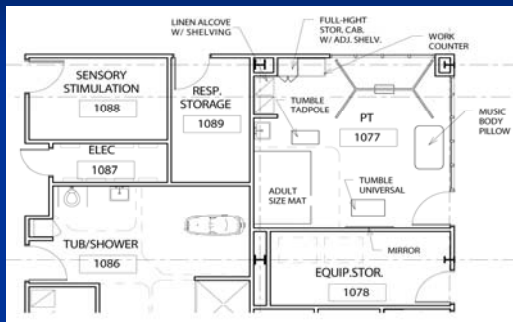
Pediatric Unit



Floor Plan



Physical Therapy



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