

## Keith Veselik, MD Medical Education Program

### Names to Know

#### A

**Almost Home Kids (AHK) Model**— the model of care developed at AHK represents a successful solution for 1) transitional care for a child with complex health care needs, 2) family training in complex medical technologies, and 3) periodic care for children and the establishment of systems for caring and competence that promote safety and quality assurance as well as child and family well-being.

#### C

**Community-based Health Care Centers**— Term used within **IL House Bill 0539** (see below) to refer to AHK and other health care centers that allow for children who are medically fragile or technology dependent to transition from the hospital to the home setting.

**Children and youth with special health care needs (CYSHCN)** — defined by the Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as:

*"Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"*

#### D

**DSCC— Division of Specialized Care for Children** is the Illinois Title V agency that provides care coordination for families and children with special health care needs. DSCC helps children with disabilities, and those who have conditions that may lead to disabilities, grow and develop to the full extent of their abilities.

#### H

**HRSA (Health and Resources and Services Administration)**—is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable.

**HUD Grant**— grant from the U.S. Department of Housing and Urban Development that serves to establish affordable housing and build strong communities.

#### I

**IL House Bill 0539**— Bill passed in 2003 allowing for the revision of the Alternative Health Care Delivery Act making possible "Children's Community-Based Health Care Centers."

## M

**MCHB (Maternal Child Health Bureau)**—is one of six Bureaus within the Health and Resources and Services Administration. It is an agency that aims to improve the physical and mental health, safety, and well-being of the maternal and child health population which includes all of the nation’s women, infants, children adolescents, and their families which include fathers and children with special health care needs.

**Medically Fragile and Technology Dependent** — Individuals who are in a stable condition but dependent on life-sustaining medications, treatments, and equipment and have a need for assistance with daily-living activities. For example, children who require mechanical ventilation daily are technology dependent, meaning that they; “use some form of medical technology, including medications and devices. If the technology were to fail or its use be discontinued, they would likely suffer a sufficiently adverse health consequence that hospitalization would be required” or else death would occur. There are at least 50,000 children nationally who are technology dependent or about 1 per 1000.

## R

**Respite care**— short-term care that offers children a comfortable place to stay with access to medical and nursing support while their parents/caregivers are unable to do so. At AHK, the amount of time can range from a 24-hour stay to one lasting up to 14 days, during which time, the child is provided with medical/nursing care and recreation activities in a secure and therapeutic environment. Families may choose this program for a variety of circumstances: temporary absences of private duty nursing care at home, parent illness, vacations, family emergencies and much needed rest.

**Respite Transportation**—Children who are medically fragile can be safely transported from their home to Almost Home Kids, under the supervision of a medical professional, for respite care. The program is a support arm of the respite care program and provides an opportunity to families that did not exist, due to the inability to safely transport a child who is dependent on medical technology.

## T

**Transitional care**—Transitional care refers to the period of time between stabilization of a child’s medical condition and their going home. Typically, patients are medically stable during the transitional period and the primary focus is on family teaching, equipping the home to care for the child, and a variety of rehabilitation or developmental goals for the child.

**Transitional care and training**—The link between hospital and home for a child who is clinically ready for discharge from a hospital, yet important factors need to be considered in order to bring the child home safely. The family may need further support through training and equipment education regarding the clinical needs of the child and/or nursing agency plan for staffing the in-home nursing hours.

**Abbreviations to know:**

**AHK:** Almost Home Kids

**CYCHCN:** Children and Youth with Special Health Care Needs

**DSCC:** Division of Specialized Care for Children

**HRSA:** The U.S. Department of Health and Human Services, Health Resources, and Services Administration

**MCHB:** Maternal and Child Health Bureau

**MFTD:** Medically Fragile, Technology Dependent

**DCFS:** Illinois Department of Children and Family Services

**DME:** Durable Medical Equipment

**EI:** Early Intervention

**EMS:** Emergency Medical Services

**DHS:** Illinois Department of Human Services

**HFS:** Healthcare & Family Services

**IDPH:** Illinois Department of Public Health