


**Prescribed Pediatric Extended
Care: Empowering Lives**


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Disclosures:

Both Presenters are employees of KYPPEC, Inc. dba
The Kidz Club, a for-profit organization.



Objectives:

- *Participants will be able to describe the role of a Prescribed Pediatric Extended Care (PPEC) in the care of children with complex medical conditions.*
- *Participants will gain an understanding of the role of nurses in relationship to a PPEC.*



Question

- ▶ What does a family with limited resources do for daycare for a child with a complex medical condition?



ANSWER:

PPEC

What is PPEC?:

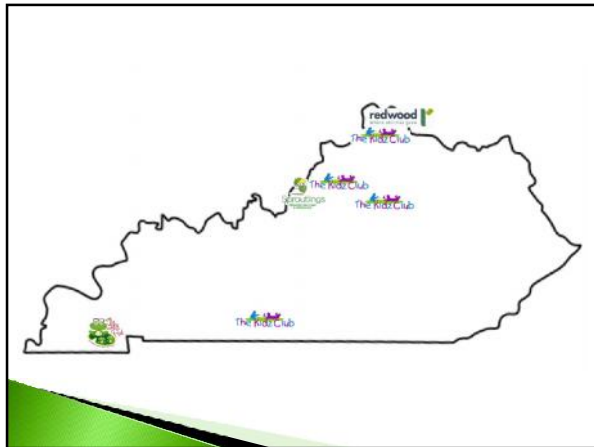


PPEC (Prescribed Pediatric Extended Care) is a non-residential health care service that provides an important link in the continuum of care for medically or technology dependent children. The PPEC center provides the following triad of necessary services for dependent children and their parents: **day health care, developmental interventions, and parental training.**

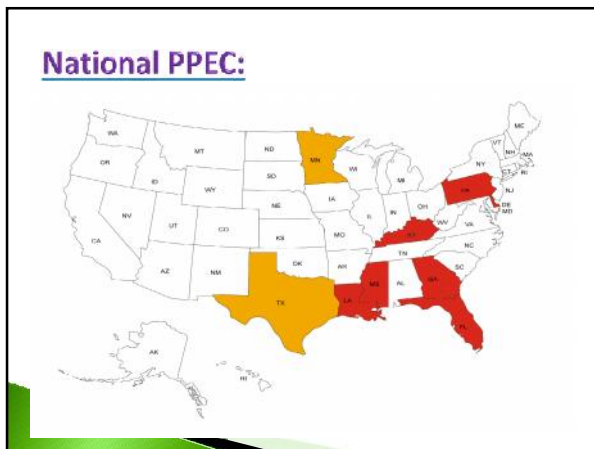
(<http://www.lrc.state.ky.us/KAR/902/020/280.htm>)

History:


- 1988 Delaware and Florida enact legislation establishing PPECs under Medicaid program (Adopted by State Boards of Health Feb 1989 effective both states in Mar 89)
- 1989 Kentucky enacts similar legislation thanks to Vicki Whitehead, RN and Carol Martin, ARNP (Adopted 1990)
- 2018 Florida over 20 organizations with over 60 centers
- 2018 Delaware has 2 organizations with 3 centers
- Kentucky 4 organizations with 9 centers



National PPEC:




Medicaid
Private Insurance




How is “medically fragile” or “medically complex” defined?:

- Technological Dependence
- Requiring “Skilled Nursing”
- Examples
- **Any child with a chronic physical medical condition that prevents the child from attending a normal daycare center.**



NOTE:

- ▶ Mental health issues do not qualify
- ▶ This is **not** “drop-in” care
- ▶ This is **not** respite care



Essential Elements:

- Child must have qualifying condition
- Staffing Requirements
- Pediatrician Medical Director
- Parental Education Component
- Parents working or attending school
- Access to ancillary therapies



Case 1:

*2 year-old girl
3-4 tonic/clonic seizures per day at 4 months of age
Parents reported developmental regression
Multiple EEGs revealed Hypsarrythmia
Diagnosed with refractory idiopathic infantile spasms and developmental delays
Treated with prednisone, Sabril, ACTH with little effect
At 1 year, child needed support to sit, could not crawl, pull up, or stand*

CASE 1 (con't):

▶ PPEC nursing care consisted of :
*Head to toe daily assessment
BID neurological assessments
Ketogenic diet (test for ketones q 2 weeks)
Therapy through First Steps (KY early intervention) with follow through therapies by PPEC staff
Consistent medication regime
Case management (link between primary, specialists, insurance provider)
Education for parents via phone and face-to-face*

CASE 1 (con't)

*Child still has intermittent seizures/spasms
Child has improved mostly with gross motor development
Crawling in quadruped position
Consistently pulling up to stand
Tolerating increasing time in gait trainer
Crawling onto and over furniture*



CASE 2:

- ▶ *One month hospitalization at birth*
- ▶ *Premature infant at 36 weeks gestation*
- ▶ *Fetal alcohol Syndrome and NAS*
- ▶ *Difficulty feeding requiring G-tube placement*
- ▶ *Hepatitis C exposure in utero*
- ▶ *Aunt given custody due to mother's inability to care for child*

CASE 2 (CON'T)

- ▶ *Guardian very concerned for her own ability to care for the child (young, no children of her own, full-time job, no family support)*
- ▶ *Made aware of PPEC services by case worker*
- ▶ *Guardian began enrollment process*
- ▶ *PPEC nurses performed initial assessment in the hospital*
- ▶ *Plan of treatment created*

CASE 2 (CON'T)

- ▶ All parties (primary physician, case worker, nurses, guardian) on board with plan
- ▶ Guardian is able to continue her full-time employment
- ▶ Education is provided at guardian's request or when intervention is needed



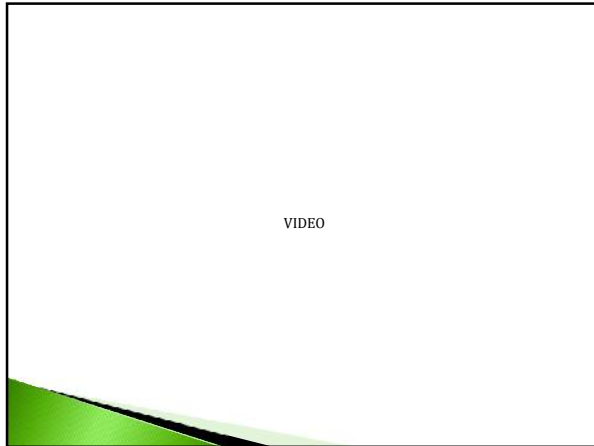
Meet Mack



Mack

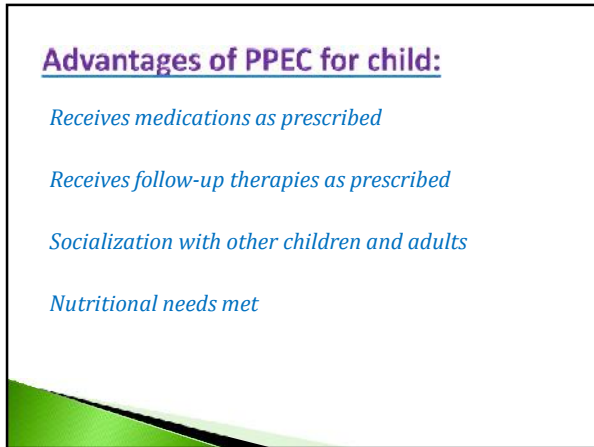
- ▶ 4 years old
- ▶ Chronic Respiratory Disease
- ▶ Epilepsy
- ▶ Dependence on Respirator [Ventilator] Status





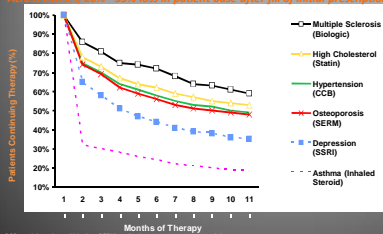
Advantages of PPEC for child:

- Receives medications as prescribed*
- Receives follow-up therapies as prescribed*
- Socialization with other children and adults*
- Nutritional needs met*



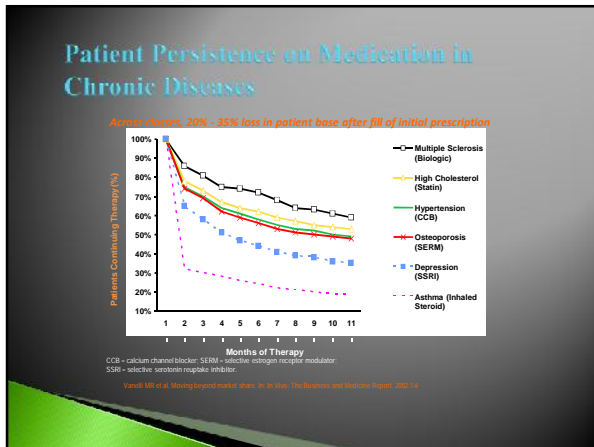
Patient Persistence on Medication in Chronic Diseases

Across classes, 20% - 35% loss in patient base after fill of initial prescription



CCB - calcium channel blocker; SERM - selective estrogen receptor modulator; SSRI - selective serotonin reuptake inhibitor.

Source: IMS et al. Moving beyond market share. In: In: *Pharm. The Business and Medicine Report*. 2012; 14.



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- Nutritional needs met*

Advantages of PPEC for Parents:

- Allows parents to work or attend school*
- Relieves some of the stress of caring for a child with a chronic illness*
- Provides a means for education concerning the child's illness and therapies*

DO THE PARENTS WORK?

- ▶ *501 Kentucky families on roll*
 - 95% of parents work or attend school*
- Erlanger*
 - 106 families*
 - 85 employed (80%)*
 - 17 students (16%)*
 - 4 disabled (4%)*

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Provides a means for education concerning the child's illness and therapies

Advantages of PPEC for Society:

Healthier children

Working parents

Improved family stability

"Medical Home" benefit

Financial ???

Questions/Comments



References:

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- Ruppert E, Host N. Out-of-Home Child Care and Medical Day Treatment Programs. In: *Guidelines for Pediatric Home Health Care*. Elk Grove Village, IL. *American Academy of Pediatrics* 2002: Chapter 34: 509-526.
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- (<http://www.lrc.state.KY.us/KAR/902/020/280.htm>)
- (<https://ahca.myflorida.com/Medicaid/childhealthservices/pppec>)
