



Children with Medical Complexity

***Office of Developmental Programs
ISAC Meeting***

October 16, 2019



Overview

- Governor's commitment to supporting **Vulnerable Populations**
- DHS initiative that takes a **"systems approach"** to understanding the challenges families are facing
- ODP - 2019-2020 Initiative
 - 10 Consolidated Waiver slots to support children with medical complexities
 - Establish a Statewide Coordinator



GOALS

01

Improve supports to families (birth, adoptive, foster) so that children can grow to full adulthood living at home with a bond to a loving adult.

02

Create family-based alternatives so that children who cannot live with birth families can grow to adulthood living in an alternative home with a bond to a loving adult.

Work Plan – 4 Areas

1. Protect Children in Facilities *and Children under general protective services*
2. Reduce the Number of Children in Facilities
3. Strengthen Services to Families to Care for Children through Age 21, Reduce Risk and Prevent Facility Admissions
4. Develop Services for Children who cannot return home with birth family or relatives

Defining Medically Complex

American Academy of Pediatrics 2016 *Recognition and Management of Medical Complexity*

- **No consensus** yet exists on recognizing complexity on the population level.
- Medical complexity is conceptually regarded as a **combination of multiorgan system involvement from chronic health condition(s), functional limitations, ongoing use of medical technology, and high resource need/use.**
- Limiting the construct of complexity to high health care resource use or multiple diagnosed medical conditions that are easily identified, without considering **associated social or functional issues**, may hamper the development of resources and policies needed to address complexity fully.

DHS Draft Definition

- **Children with Medical Complexity (CMC) have: chronic, severe health conditions; substantial health service needs, often with reliance on or use of medical technologies; functional limitation; and high health resource utilization.**



The Kids Grow Up 2019 Age Outs



240 children

60 with quadriplegia

62 with G Tubes

86 with autism/PDD

1 in CYF Custody



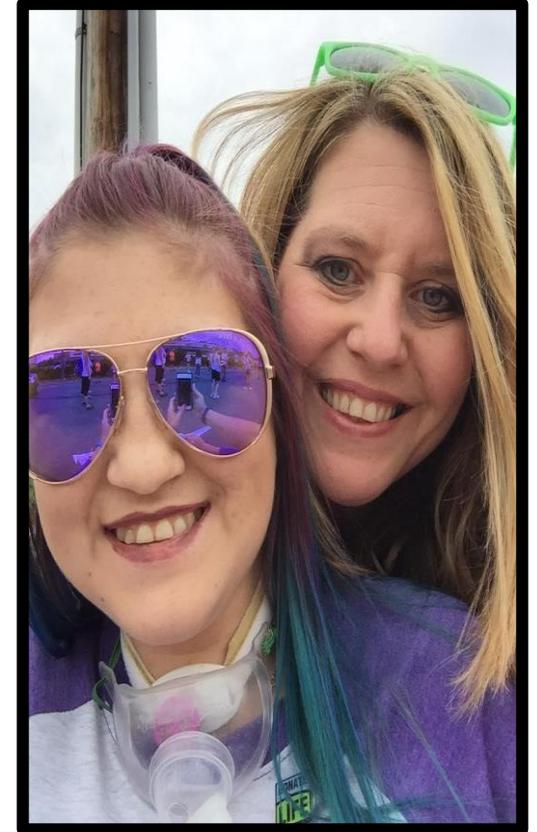
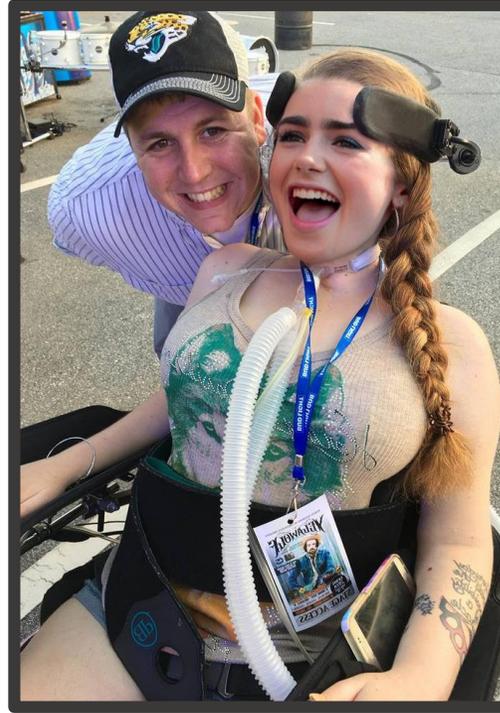
190 referred to ODP

39 referred to OLTL

Remainder unidentified



**6 from residential
facilities**



Disrupted Attachment Results in Dysregulation

Without a familiar and reliable mother to respond, babies detach and live in a state of constant erupting fear. **Dysregulation** is the result. Dysregulation: disruption of rhythms of the body leads to difficulty with affect self-regulation and sensory self-regulation.

Affect Regulation/Emotional Regulation

- The ability to modulate our emotional state in order to adaptively meet the demands of the environment. When children have a difficult time with affect self-regulation, we observe maladaptive behavior or response to the environment:
 - Sleep disorders
 - Anger management/impulse control
 - Depression/anxiety
 - Gastrointestinal problems
 - Physical coordination

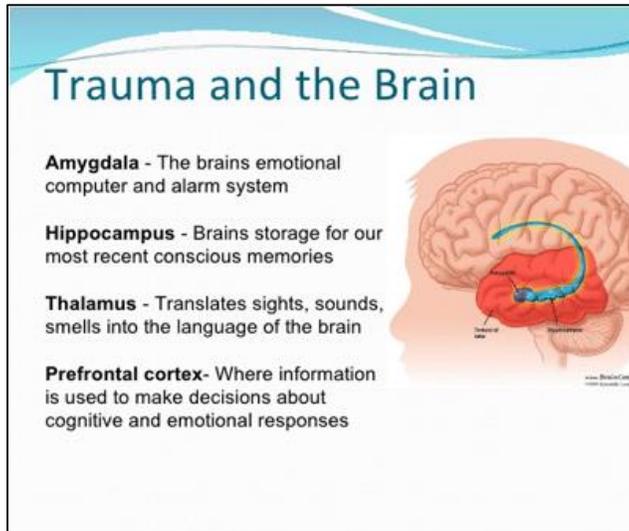
Sensory Regulation

- The ability to adjust or regulate the level of alertness depending on the time of the day and the stimuli presented... When children have a difficult time with sensory self-regulation, we observe maladaptive behavior or response to the environment and sensory stimuli.
 - Extreme response to or fear of sudden, high-pitched, loud, or metallic noises like flushing toilets, clanking silverware, or other noises that seem unoffensive to others
 - Distracted by background noises others don't seem to hear
 - Fearful of surprise touch, avoids hugs and cuddling even with familiar adults
 - Fearful of crowds or avoids standing in close proximity to others

Disrupted Attachment results in Developmental Trauma

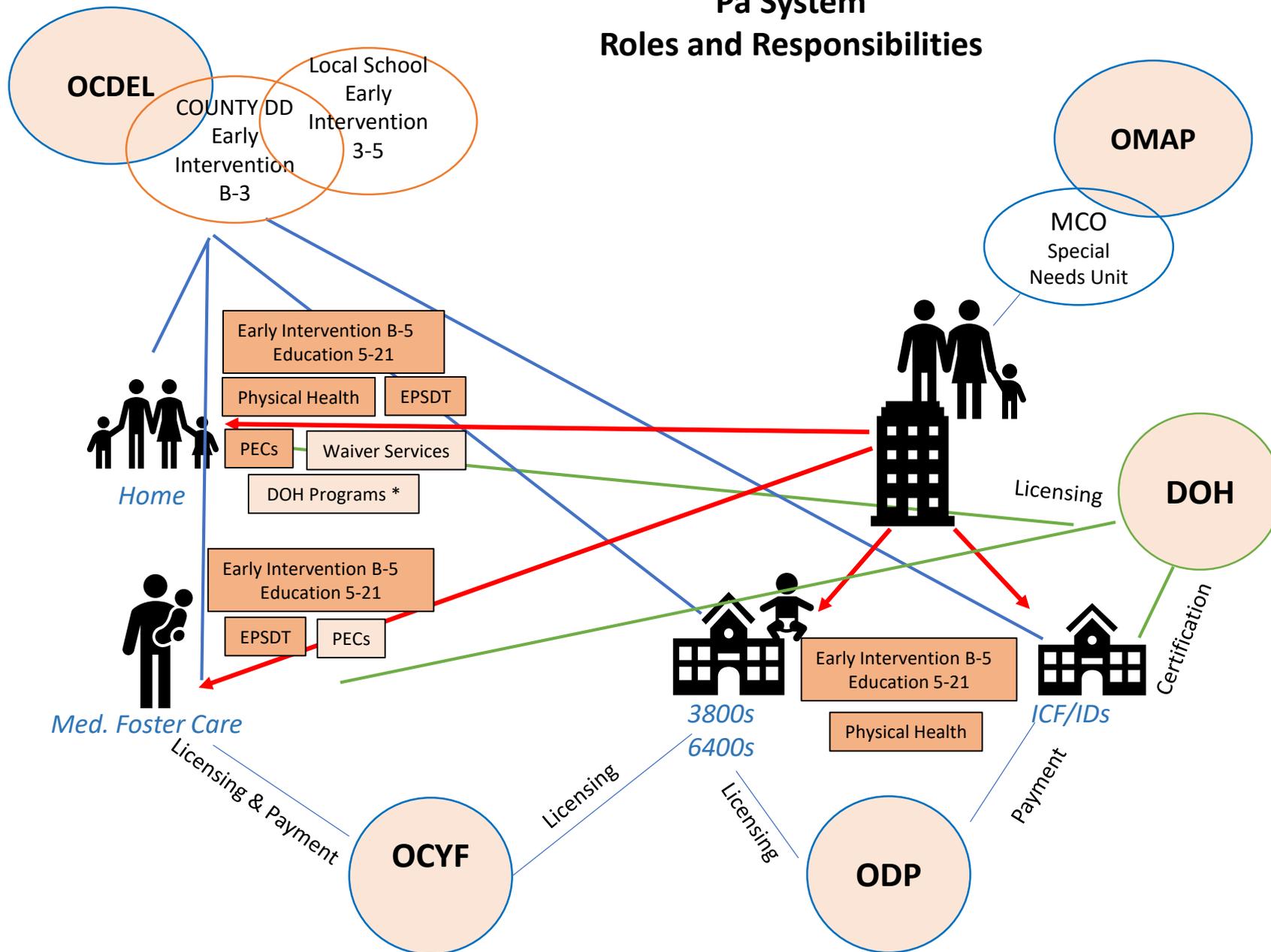
Amygdala – over excitement (fight or flight) precludes the other parts of the brain from functioning.

- Hippocampus (memory)
- Thalamus (language)
- Prefrontal Cortex (decision-making and emotional management)



- Developmental Trauma, because it occurs during critical developmental stages, impedes development
- **Developmental Trauma (DT) outcomes**
 - Sensory processing disorder
 - ADHD
 - Oppositional defiant disorder
 - Bi-polar
 - Personality disorder (especially borderline personality disorder)
 - PTSD
 - Cognitive impairment
 - Speech delay
 - Learning disabilities

Pa System Roles and Responsibilities



Responsibilities

Payment

OMAP
Hospital
EPSDT I home
PECs
Med Foster Care
OCDEL
Early Intervention
OCYF
Med Foster Care
ODP
ICF/ID

Service Quality

OMAP
Hospital
EPSDT
OCDEL
Early Intervention
OCYF
Med Foster Care
3800s
ODP and DOH
ICF/ID
6400s
DOH
PECS

Permanency

OCYF Med Foster Care – age 21

DOH Programs

- TACH* – Tech. Assisted Children's Home Program
- TBI Return to Learn – school age
- Epilepsy Education
- Special Kids Network - Help Line and Home nurse visits in rural PA for 500 kids at 300% of poverty
- Phila Special Needs Consortium
Specialty Care Program: Child Rehabilitation Program (neuro/ortho); Sickle Cell, Spina Bifida; Cystic Fibrosis; Hemophilia; Cooley's anemia
- TBI Grant – juvenile justice; adults;
- PECCs – Pediatric Extended Care Centers



Barriers to Supporting Children at Home

Every Child Deserves a Home Coalition Study

- It is a **“fragmented maze.”** Information and resources are very difficult for families to obtain.
- **Interactions with the service system are too often negative, impersonal, and problematic.** Families’ voices are not heard and their experiences are not widely understood.
- Insurance and Medicaid **require hours of work from families** and are a source of **“constant battles”** for families to obtain covered services.
- **Families lack adequate amounts and types of supports** (respite, physical adaptations to homes and vehicles, assistance when not at work).
- **Families are fearful about the long-term stability of supports**
- Families, children, and young adults are often **socially isolated, housebound,** or interact only with health care or disability services providers.

County Early Intervention programs

Medical professionals still recommend that families institutionalize their children.

Provider Agencies and Families

Families are often overcome with exhaustion by the time of adolescence and look for placement.



TEXAS



- Help families explore family options to facility care for their children with disabilities
 - To live at home, or
 - To live with a Support Family if they can't live at home.
- Lead permanency planning for children living in Texas nursing facilities.
- Recruit and prepare Support Families for children who cannot live at home.
- Assist service provider organizations to increase their capacity to provide family-based options.
- Provide training and technical assistance to family groups and community organizations on family supports
- Develop educational materials and tools on family-based alternatives to institutional care.
- Work with state policy-makers and decision-makers to remove barriers and build better support for families.

From Institutions to Families

563

Number of children EveryChild has helped move or be diverted from institutions to families.

37%

Percent of children EveryChild helped return home.

63%

Percent of children EveryChild helped move to a Support Family.

61%

Overall decrease in number of children with disabilities in large Texas institutions since 2002.

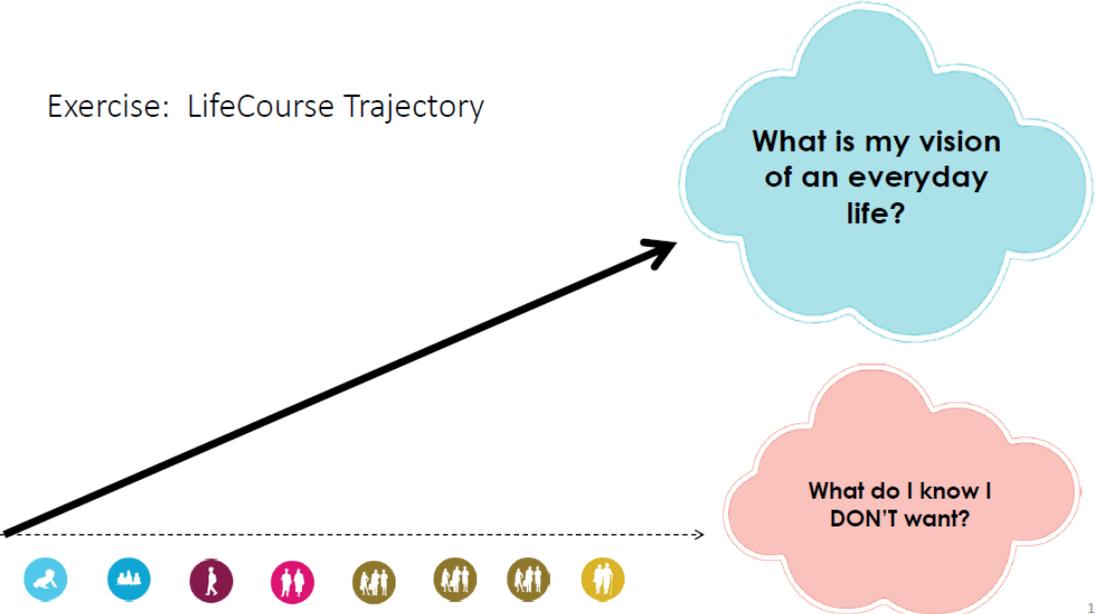


State Programs and Approaches to Support Permanency

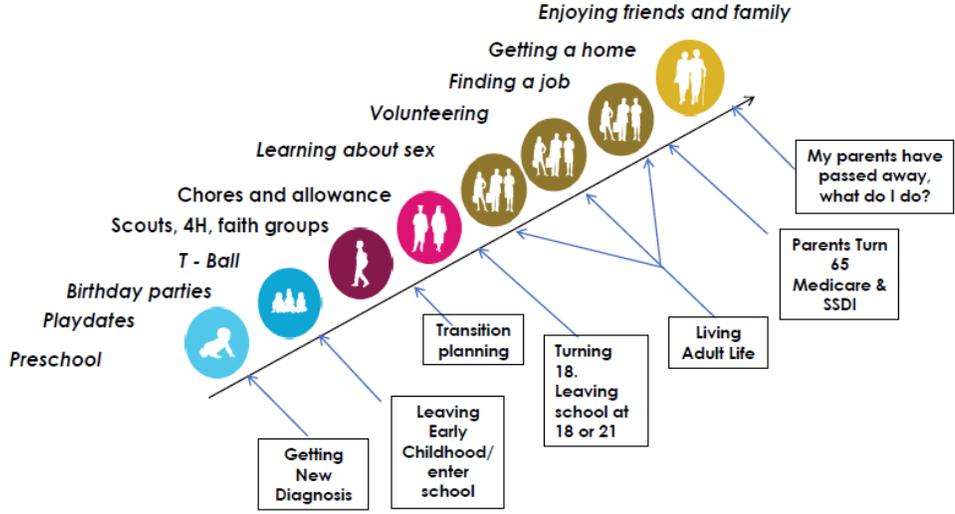
- Family Support and non-medical in-homes services for
 - Birth families
 - Adoptive families
 - Foster families
- Paying family members as care givers
- Allowing families to direct services with
 - Hiring/firing authority
 - Flexible budgets so they can prioritize services
- Develop Life Sharing for children whose birth/adoptive families are unable to care for them

Anticipatory Guidance and Support: Planning for the Immediate and Long-Term Future and Preparing for Transitions Throughout Life

Exercise: LifeCourse Trajectory



Life Experiences and Life Transitions Anticipatory Guidance for Life Experiences



DISCUSSION