

Supports Coordination Organizations: Changes to TSM, Supporting Individuals with Medical Complexities

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Kristin Ahrens
ODP Deputy Secretary



Agenda

- Overview of Children with Medical Complexities initiative
- Targeted Support Management (TSM) changes
- Role of Supports Coordinators
- Available waiver services
- Training Plan for AEs and SCs





Children
need
loving
and
caring
adults

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.

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.

Three Focus Areas

1. Provide children living in facilities with the opportunity for family life

- Budget and plan for children to transition to the family home
- Family Facilitator to transition children
- Expand and improve HCBS services to support them
- Develop Life Sharing for children who cannot go home with family

2. Ensure the health and welfare of children in facilities

- Regulatory changes and regulatory compliance guidance for inspections for facilities serving children with medical complexities
- Enhance licensing inspection teams with nurses and trained staff
- Provide technical assistance, training to support agencies

3. Strengthen services to families with children with complex care needs through Age 21

- Register all eligible children with county ID/A agencies
- Improve coordination and delivery of physical health services including skilled nursing
- Expand and customize the ODP HCBS waiver to include children with complex care needs, ages birth - 21

Actions Implemented

✓ **Family Facilitator Started (Jan 2020)**

- SE HCQU/PCHC - Jennifer Harniman Crangle, MSW, LSW

✓ **Interagency work group established – ODP, OMAP, OCYF (Dec 2019)**

- Monitor admissions, length of stay and discharges
- Identify Children to transition home
- Facilitate transition of children to family homes by working with MCOs, facilities, family facilitator and county ID/A and CYF agencies.

✓ **ODP Special Populations Unit (Dec 2019)**

- Manage the DHS interagency work group and family facilitator role
 - Data tracking and measuring outcomes
- Improve Residential facilities
 - Training on best practice
 - Transformation to transitional services
- Train Home Based Service providers

✓ **Waiting list initiatives inclusion of CMC population (2020 and 2021)**

✓ **Research, stakeholder engagement for policy changes**

- TSM, waiver, referral bulletin

Defining Medically Complex in PA

1. Have a medically complex condition defined as one or more chronic health conditions that meet both of the following:
 - (a) cumulatively affect three or more organ systems; and
 - (b) require medically necessary nursing intervention to execute medical regimens to use technology for respiration, nutrition, medication administration or other bodily functions;
2. Individual is 21 years of age or younger;
3. Have substantial adaptive skills deficits in three or more areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction and/or capacity for independent living based on a standardized adaptive functioning test; and
4. Be recommended for an ICF/ORC level of care based on a medical evaluation.

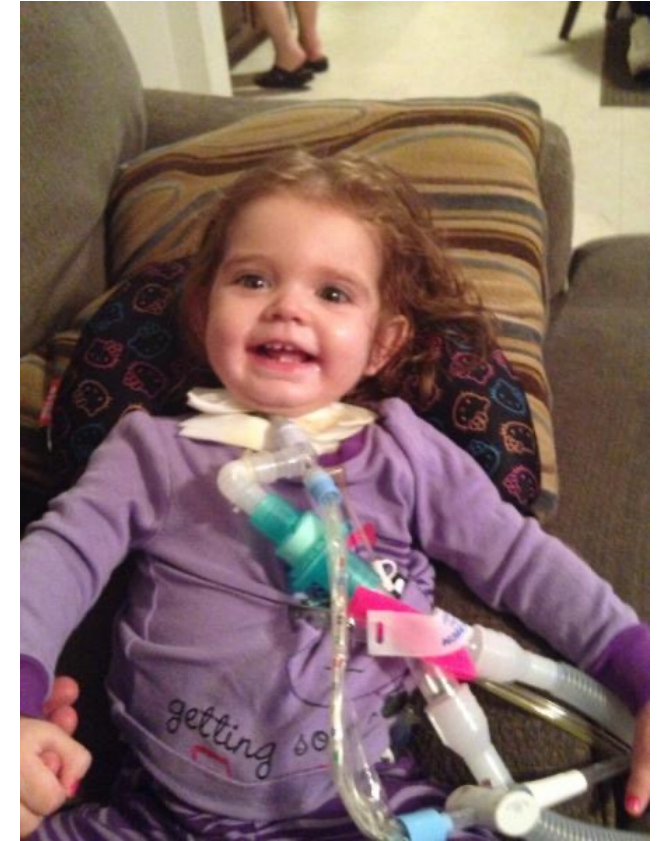
Children Who are Medically Complex in PA

Mercer Analysis (2019 claims data)

240 children with medical complexities in congregate settings

2,709 children with similar diagnostic profiles in community settings (1,380 of these children used more than 120 hours of home health services annually)

448 children enrolled for Pediatric Extended Care Center (PECC) services in 2018





Barriers to Supporting Children at Home



Top Barriers identified by PH-MCOs

- Family unwilling to provide care even with training
- Physical plant of the home unable to support member
- Child in custody of OCYF and no foster family available
- Training needs of the family not yet met
- Acuity of member precludes discharge even with supports
- Family physically or emotionally unable to provide care

Dr. Renee Turchi Study

- Home nursing is essential but fraught with difficulties – untrained and unreliable nursing staff and home health aides
- Frightened when they learn that their child has a trach
- Overwhelmed and sad
- Training helps but it needs to be individualized
- Even when prepared to go home, transition difficult

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.



The Role of the Family Facilitator

- Helps children move from medical settings back into family homes or with alternative families
- Provides information and facilitate linkages to community supports, services, providers, service coordinators and advocacy resources to families
- Helps families obtain necessary training to safely support children in family homes



SC ROLE IN INDIVIDUAL MONITORING FOR CHILDREN WITH MEDICAL COMPLEXITIES

- **Purpose:** Monitoring is designed to provide support to individuals and their families, allows for frequent communication to address current needs and to ensure individuals health and safety. In addition, monitoring allows for increased support to plan for services throughout the lifespan.
- **Requirement:** TSM monitoring must take place at least annually. *Monitorings can occur at a greater frequency to ensure the health and welfare of the individual.*
 - *Monitoring frequency for individuals with medical complexities will vary based on the unique needs of each individual.*

SC MONITORING TOOL CHANGES

The SC Monitoring Tool Supports Coordination Guidance Document is being updated to include guidance to several questions to assist SCs when monitoring children and individuals with medical complexities.

- **Question 1:** Have there been changes observed in the individual's overall health functioning and health status since the last monitoring?
- **Example of new guidance for Q1:** Consideration for children: Weight/height charted on growth chart – documentation from health care practitioner. Are they eating? Has there been a change in their appetite? Consideration for individuals with medical complexities: Tracheostomies: is the site free of discolored drainage and odor? Is the equipment clean? Has there been any accidental or unscheduled removal of the tracheostomy tube?

The goal is to issue updated guidance document to the field and embed in the CMC Overview of Medical Support Needs Training targeted for January 2022.

RESOURCES FOR THE SC SUPPORTING A CHILD WITH MEDICAL COMPLEXITIES

Charting the Lifecourse tools and resources

Special Needs Units (SNU)

Family Facilitator

Health Care Quality Units (HCQU)

ODP Nursing and Clinical staff

IMPORTANCE OF A COORDINATED TEAM

- Children with Medical Complexities may have large teams and it will be the job of the SC to help connect the team members. Teams may consist of many of the following:
 - Families
 - Educators
 - Health Insurance (SNU)
 - Early Intervention
 - Waiver providers
 - Behavioral health providers
 - Medical providers

TSM Eligibility Overview

1. An individual with a medically complex condition must meet four criteria to be determined eligible for an ICF/ORC level of care:

- A licensed physician, including a developmental pediatrician, licensed physician's assistant or certified registered nurse practitioner must certify that the individual has a medically complex condition which is a chronic health condition that affects three or more organ systems and that the individual requires medically necessary skilled nursing intervention to execute medical regimens to use technology for respiration, nutrition, medication administration or other bodily functions.

2. A QDDP who meets the criteria established in 42 CFR § 483.430(a) must certify that the individual has impairments in adaptive functioning based on the results of a standardized assessment of adaptive functioning which shows that the individual has substantial adaptive skill deficits in three or more of the following areas of major life activity:

- Self-care;
- Understanding and use of language;
- Learning;
- Mobility;
- Self-direction; and
- Capacity for independent living

3. The individual is age 0-21 and documentation substantiates that the individual's medically complex condition and substantial adaptive skill deficits manifested prior to age 22.

4. Documentation of a current medical evaluation performed by a licensed physician, physician's assistant, or certified registered nurse practitioner that states that the individual is recommended for ICF/ORC level of care or an MA 51 form completed by a licensed physician, physician's assistant, or certified registered nurse practitioner may be submitted to document that the individual is recommended for an ICF/ORC level of care .

Waiver Services that Support Children with Medical Complexity

- Gap analysis, consult with Texas Every Child, Imagine Different input identified service gaps
- The following waiver changes designed to address:
 - Homemaker/chore – infection control
 - Home accessibility – 180 days prior to transition from institutional settings
 - Lifesharing – enhancements in service definition, provider qualification, rates
 - Family Support Assistance - NEW

Family Medical Support Assistance

Two Components:

- 1. Family Support Assistant: provides assistance to individuals and their families with coordination of unpaid and waiver services
- 2. Nursing Oversight – By a licensed nurse to do assessments, Health Risk Screening Tool Clinical Reviews, Identification of training needs, etc.

Family Support Assistant

- Scheduling medical and behavioral health appointments
- Directly assisting with the discharge process from a hospital, clinic, or nursing home setting with going home.
- Assisting in obtaining needed medication, supplies, and equipment;
- Assisting with implementation of the service plan and life course plan with the family;
- Providing training and consultative assistance on implementation of non-medical aspects of the ISP to the family or Children Youth and Family supervised family and team members; and
- Training staff supports coming into the home on non-medical aspects of the ISP and roles and responsibilities of team members of implementation of non-medical aspects of the ISP.

Nursing Oversight

- Assessment of the participant's medically complex condition;
- Completion of Health Risk Screening Tool Clinical Reviews;
- Identification of training needs related to the participant's medically complex condition and providing training;
- Helping designated persons with the impact on the participant's behavioral or emotional health;
- Consulting with doctors and other healthcare professionals; and
- Supervision and evaluation of the participant's medical and/or behavioral health needs or anything that maintains the participant's best state of health.



Training Plan

- TSM bulletin training
- Training for QDDPs
- Overview of Medical Support Needs
- Specific topic areas from Regulatory Compliance Guide
 - Infection Control
 - Respiratory Assistance
 - Nutritional intake assistance
 - Skin care & Elimination assistance
 - Developmental Support