

# Caring for Children with Special Health Needs

# Participant Guide

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DCS Office of Training and Professional Development





# Caring for Children with Special Health Needs

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# Share the following:



- Name
- How long you have been a foster parent?
- Something unique about your family.



# Objectives

#### Participants will:

- Have an understanding that Medical Fragile children have specific diagnosis.
- Become familiar with the services available for children with special medical needs.
- Gain an understanding of their role as foster parents and the skills necessary to maintain a special needs child in the home.
- Learn how Self- Care is essential to their effectiveness.
- Review tips for optimal care of the youth in their care.

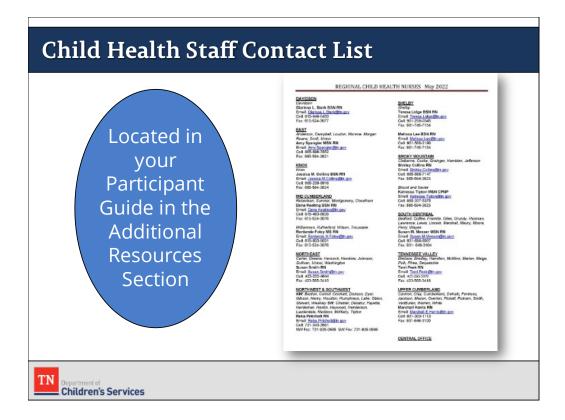
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# Children with special Healthcare Needs

Children with Special Healthcare needs are defined as having at least one chronic physical condition that results in prolonged dependency on medical care.







# Special Healthcare Needs

- Some children may need oxygen or special monitors
- Some children may require special formula or diets
- Some children may have an alternate method of feeding i.e. G-tube





# Special Healthcare Needs

Some children with special healthcare needs are prone to multiple hospitalizations such as traumatic brain injury, organ transplants, ventilator dependent.





# Specialist Fast Round Activity



- Divide into 2 groups/teams
- Choose a team captain
- Find the right definition for the specialist that is shown using your participant guides.
- You have 10 seconds



|                    | A <b>Neurologist</b> is a doctor who specializes  |
|--------------------|---|
| Neurologist        | in treating diseases of the nervous system. The nervous system comprises the central and peripheral nervous system. This complex system involves the spinal cord and the brain.   |
| Gastrologist       | Gastroenterologists diagnose and treat disorders of the stomach, intestines, liver, and pancreas, including ulcers, tumors, inflammatory diseases (including ulcerative colitis and ileitis), and rectal disorders.   |
| Cardiologist       | A <b>Cardiologist</b> is a doctor with special training and skill in finding, treating, and preventing diseases of the heart and blood vessels.   |
| Urologist          | A <b>Urologist</b> is a physician who has specialized knowledge and skill regarding problems of the male and female urinary tract and the male reproductive organs.   |
| Orthopedist        | Medical specialty concerned with the skeleton and its associated structures.  Orthopedists treat fractures, strained muscles, torn ligaments and tendons, and other injuries and deal with acquired and congenital skeletal deformities and the effects of degenerative diseases such as osteoarthritis |
| Physical Therapist | Physical Therapists (PTs) are highly educated, licensed healthcare professionals who can help patients reduce pain and improve or restore mobility - in many cases without expensive surgery and often reducing the need for long-term use of prescription medications and their side effects.          |

| Occupational Therapist          | Occupational therapy is a health profession whose goal is to help people achieve independence, meaning and satisfaction in all aspects of their lives. <b>Occupational Therapists:</b> Apply their specific knowledge to enable people to engage in activities of daily living that have personal meaning and value.  |
|---------------------------------|---|
| Speech Therapist                | Speech and Language Therapists (SLTs) work closely with infants, children and adults who have various levels of speech, language and communication problems, and with those who have swallowing, drinking or eating difficulties.   |
| Endocrinologist                 | An <b>Endocrinologist</b> is a physician who specializes in treating disorders of the endocrine system, such as diabetes, hyperthyroidism, premature sexual maturation, and many others. <b>Premature sexual maturation</b> is a general term (which includes precocious puberty and other disorders) and implies the onset of sexual characteristics (e.g., breast development or pubic hair) below the age of 8 years in girls and 9 years in boys. |
| Pulmonologist                   | A <b>Pulmonologist</b> is a doctor who has special training in diagnosing and treating diseases of the lungs. Also called pulmonary specialist.   |
| Optometrist vs. Ophthalmologist | <b>Optometrists</b> examine, diagnose, and treat patients' eyes. <b>Ophthalmologists</b> are  |

|             | eye doctors who perform medical and             |
|-------------|---|
|             | surgical treatments for eye conditions.         |
|             | <b>Neuro-Ophthalmology</b> is a subspecialty of |
|             | both neurology and ophthalmology. Neuro         |
|             | ophthalmologists specialize in vision           |
|             | problems that relate to your nervous            |
|             | system. Such issues include vision              |
|             | problems due to traumatic brain injuries or     |
|             | diseases, including trauma, a stroke, or an     |
|             | infection.                                      |
|             | Audiologists are health care                    |
|             | professionals who identify, assess,             |
|             | and manage disorders of hearing,                |
|             |   |
| Audiologist | balance, and other neural systems.              |
|             |   |
|             |   |
|             |   |
|             |   |

Participant Guide

# Therapeutic Needs and Supports

# Occupational or Speech Therapists

Some children may require therapy for feeding problems which can be provided by either an occupational or speech therapist.





# Therapeutic Needs and Supports

### Respiratory Therapists/Services

Often children will require respiratory or nursing services to assist the resource parent in providing respiratory and other specialized care in the home.





# Therapeutic Needs and Supports

#### **Home Health Services**

Most of all services for children will be provided by a local home health agency upon a written referral by the child's physician.





# Therapeutic Needs and Supports





#### **TennCare**

TENNCare evaluates coverage of services for children.



# Therapeutic Needs and Supports



#### Case Management Services

TennCare Select will provide a medical case manager for your child.



| Occupational or Speech<br>Therapists            | Some children may require therapy for feeding problems which can be provided by either an occupational or speech therapist.  |
|---|--|
| Respiratory<br>Therapists/Services              | Often children will require respiratory or nursing services to assist the resource parent in providing respiratory and other specialized care in the home. Some children may need breathing treatments due to their chronic disease processes.                                     |
| Home Health Services and<br>Private Duty Nurses | The above-mentioned services will be provided by a local home health agency upon a written referral by the child's physician. The doctor will need to indicate the number of hours.  |
| TENN CARE                                       | TENNCare evaluates coverage of services for children.  |
| Case Management Services                        | In some circumstances, TennCare /BlueCare Select will provide a medical case manager for your child. This is a nurse that can assist you in obtaining and coordinating appointments with specialists and therapists and assist in obtaining supplies and equipment for your child. |



# **Individuals with Disabilities Education Act**

Individuals with Disabilities Education Act (IDEA) defines intellectual disabilities as, "significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance."



## Individuals with Disabilities Education Act

Intellectual disabilities are not diseases, nor should they be confused with mental illness. Children with intellectual disabilities become functional adults; they are able to learn, but do so slowly, and with difficulty.





# **IDEA Requires**

Individuals with Disabilities
Education Act (IDEA) requires
that all children suspected of
having a disability be evaluated to
determine if they have a disability
and, because of the disability, need
special services under IDEA



# Managing your Time



- Establish a routine for mealtimes
- Give medications at a time when there is not much confusion to avoid errors
- Naps are important for children with special medical needs. Establish a routine and provide an environment which will promote sleep at nap times.



# Managing your Time



- A set bedtime is important to the routine of your home, you, as well as the child. It will ensure the child receives the rest they need as well as time for yourself and your needed rest.
- Remember routines help the child feel secure.



# Your Role



Planner someone that organizes activities and ensures that meetings and appointments are met.



# **Your Role**

Advocate someone that supports and works on the behalf of another for action.





# **Your Role**



Negotiator someone that discusses a problem with the aim of achieving agreement between people or groups of people.



# Notes:

# Tips to Navigate Your Roles

- Keep all your medical supplies and equipment in one place
- Make a list of all supplies that will be used on a regular basis
- Coordinate all appointments with your child's schedule (do not schedule things such as physical therapy at a time when your child naps or at feeding times)





# Tips to Navigate Your Roles

- Discuss time changes as needed with therapists when it interferes with your child's routine or schedule
- Be honest with the therapist about how much time you will have for the therapy
- Keep a journal and a daily calendar handy





# Tips to Navigate Your Roles

- Assign your child a place to keep his school related materials-his books, his homework, school notices, lunch money, supplies, etc.
   Mornings will run more smoothly if all his things are kept in one place.
- A specific time and place should be set aside for homework assignments, and let your child know you are going to stick to the plan.





# Tips to Navigate Your Roles

Parents should request Health Notebook from Blue Cross Blue Shield, add process and contact information.





## **Self-Care Ideas**

- Divide into 3 to 4 groups.
- Brainstorm ways to avoid burn out and add them to the top of the flipchart.
- At the bottom half of the flipchart brainstorm ideas for self-care, that are free.
- You may add a few that may cost.
- Share with class.







# **Placement Changes Note:**

- If a change in placement occurs, including <u>respite</u> or transition to the parent/guardian or adoptive home, the FSW/JSW and/or the Contract Provider must consult with the Regional Health Nurse prior to making the move.
- The nurse can aid in coordinating with health care providers, advice on training requirements, and assessment and transfer of medical equipment, supplies, and other needs.



# CONFIDENTIAL Children's Services

# **Achieve Optimal Care**



- Meet with other foster parents who have had experience with children with special needs or join support groups for the particular disability affecting your child.
- Don't let the disability define the child. Look for the child's unique and positive qualities.
- Keep informed about the child's developmental abilities as well as needs.



# **Achieve Optimal Care**

- Plan your day but take things one day at a time (or sometimes one hour at a time).
- Enjoy the times when the child is doing well.
- Save time for your children and your significant other.







# **Seven-Types of Self- Care Activities for Coping with Stress**

#### 1. **SENSORY**

When you feel stressed and need to calm your mind, try focusing on the sensations around you—sights, smells, sounds, tastes, touch... This will help you focus on the present moment, giving you a break from your worries.

- Breathe in fresh air.
- Snuggle under a cozy blanket.
- Listen to running water.
- Sit outdoors by a fire-pit, watching the flames and listening to the night sounds.
- Take a hot shower or a warm bath.
- Get a massage.

- Cuddle with a pet.
- Pay attention to your breathing.
- Burn a scented candle.
- Wiggle your bare feet in overgrown grass.

#### 2. PLEASURE

A great way to take care of yourself when you're coping with stress is to engage in a pleasurable activity. Try one of these ideas.

- Take yourself out to eat.
- Be a tourist in your own city.
- Garden.
- Watch a movie.
- Make art. Do a craft project.
- Journal.
- Walk your dogs.
- Go for a photo walk.

#### 3. MENTAL/MASTERY

You can also give yourself a boost by doing a task that you've been avoiding or challenging your brain in a novel way. This can also boost self-confidence.

- Take action (one small step) on something you've been avoiding.
- Try a new activity.
- Drive to a new place.
- Make a list.
- Immerse yourself in a crossword puzzle.
- Do a word search.
- Read something on a topic you wouldn't normally.

#### 4. SPIRITUAL

Getting in touch with your values—what really matters—is a sure way to cope with stress and foster a calm mind. Activities that people define as spiritual are very personal. Here are a few ideas:

- Attend church.
- Read poetry or inspiring quotes.
- Light a candle.
- Meditate.
- Write in a journal
- Spend time in nature.
- Pray.
- List five things you're grateful for.

#### 5. **EMOTIONAL**

Dealing with our emotions can be challenging when we're coping with stress. We tend to label emotions as "good" or "bad," but this isn't helpful. Instead:

- Accept your feelings. They're all ok. Really.
- Write your feelings down. Here's a list of feeling words.
- Cry when you need to.
- Laugh when you can.

#### 6. PHYSICAL

Coping with stress by engaging the body is great because you can bypass a lot of unhelpful mental chatter. It's hard to feel stressed when you're doing one of these self-care activities:

- Try yoga.
- Go for a walk or a run.
- Dance.
- Stretch.
- Go for a bike ride.

- Don't skip sleep to get things done.
- Take a nap.

#### 7. SOCIAL

Connecting with others is an important part of self-care. This can mean activities such as:

- Participating in a book club.
- Joining a support group.
- Go on a lunch date with a good friend.
- Calling a friend on the phone

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#### **Dental Services for Children with Disabilities**

From Policy 20.12 Dental Services:

All children aged 12 months and older should receive an initial dental examination within 30 days of coming into custody and then every 6 months thereafter.

Children with developmental Disabilities and/or Special Needs

Children/youth with special needs that require sedation for a dental exam and treatment may receive an EPSDT Dental exam once a year rather than every six (6) months.

\*

#### **Tennessee Early Intervention Service TEIS**

The Tennessee Early Intervention System (TEIS) is a program that provides services to children ages birth up to age three who have disabilities or other developmental delays. The TEIS program is a critically important program to supporting young children and their families to reach their optimal development.

From EPSDT Policy 20.7 Protocol:

Children Under Age Three (3) Years Old

When a child under age 3 comes into custody, and especially if there are any concerns the child may be experiencing any type of disability or medical condition, a referral to Tennessee Early Intervention System (TEIS) is made.

Children aged three (3) and older are referred to the local school system for evaluation.

#### **Assistive Technology**

Assistive technology is a broad term that includes any device or piece of equipment that can be used to help a person perform some type of activity or improve their ability to function.

An assistive technology device is any item, piece of equipment, or product system, whether acquired commercially or off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of children with disabilities. These devices can include high-tech equipment like computers, but also simple magnifiers, splints, pointers, and ramps. The single most important characteristic of an assistive device, whether it is high- or low-tech, is its ability to meeting the specific and individual needs of you child.

Examples may be as simple as adapted utensils for a child to feed themselves or as complicated as augmentative-communication devices to supplement a child's natural speech and communication.

#### **Respite Services**

Respite services are available to medically fragile foster parents for up to two (2) days per month or a maximum of twenty-four (24) days of respite per fiscal year (See Guidelines to Supplemental Respite Care, Policy Attachment: 16.8). The contract agency should identify a respite home within 2-4 weeks of the child placement so respite services will be available as soon as possible.

Respite caregivers must be trained in the specific care of the CSHCN by a medical professional. The DCS Nurse can assist in coordinating with health care providers and advise on training requirements.