CHILDREN WITH SPECIAL HEALTH CARE NEEDS SERVICES PROGRAM

Client Guide

Si necesita esta guía en español, llámenos gratis al 877-888-2350.

TEXAS
Health and Human Services
Medical and Social Services

Pub. No. E07-12357

Welcome to the Children with Special Health Care Needs (CSHCN) Services Program.

This is your *CSHCN Services Program Client Guide*. Inside, you will find important information about your new benefits and answers to many of your questions.

You're receiving this guide because you've been approved to be in the CSHCN Services Program. This means that your application has been received, reviewed, and approved because you meet the criteria to be in the program.

This packet is divided into sections for easy reference:

You can always learn more about our program at **hhs.texas.gov/services/disability/children-special-health-care-needs-program**. You can also access this guide online.

For help, call us at **800-252-8023** or email us at **cshcn@hhs.texas.gov**.

CSHCN SERVICES PROGRAM ELIGIBILITY

This section covers everything you need to know about what it means to be eligible for benefits, how to keep eligibility, and what happens if you don't renew it on time.

What it Means to be Eligible

Being eligible means coming off the waiting list and being able to get benefits. Now that you are eligible, you should have received a **Notice of Eligibility (NOE)**. It is a sheet of paper with your name, ID number, and eligibility dates (when coverage starts and ends).

You *must* show the notice of eligibility each time you visit your provider's office. If you don't, you might get billed.

When you reapply for the program and are found eligible again, you'll receive a new notice. Always use the newest one when visiting your health care providers.

Maintaining Eligibility

Beware of your eligibility dates! You can only get benefits during that time frame. When your eligibility period ends, you'll no longer be covered by our program. To maintain your eligibility, **you must reapply every 12 months**.

It is very important to reapply on time. If you don't, you will be placed back on the waiting list.

Renewing your Application

When the time comes to renew your application, we'll send you a renewal packet. The packet includes the application and a letter with next steps. Read the renewal packet carefully. If you don't receive a renewal packet 60 days before your eligibility runs out, call **800-252-8023**. Application forms are also available for download from our website.

Each time you renew your application, you must supply proofs of residency, income, and any other insurance coverage (including Medicaid or CHIP coverage). You don't need to submit proof of date of birth. Please include any information that has changed since the last time you applied, such as changes in:

- Address and phone number
- Number of people living in your home
- Income
- Insurance (including premiums)

Along with the application, you must send in a new Physician/Dentist Assessment Form (PAF). Deadlines are on the letter.

Always write your name and client ID number on all proofs, forms, and letters that you send to us. Keep copies of everything for your records.

If you need help, a case manager in your health services office can help you gather any paperwork you need and can check to see if you are still eligible for our program. If you still meet the eligibility criteria when you reapply, you'll keep your benefits.

Fill in a new application every 12 months and turn in to your health services office.

Do not miss the deadline! If it is close to the end of the eligibility date but you're having trouble gathering all of the required documents, send in the application forms you have completed. Then, send the rest of it as soon as possible.

The Waiting List

If you're initially placed on the waiting list or are placed back on the waiting list, you must still reapply every 12 months. You'll have to wait until we have enough funds to cover your benefits again.

Avoid going back to the waiting list by filling in a new application every 12 months and turning in to your health services office.

When considering when to move you off of the waiting list, we review different information, such as:

- Your physician or dentist's statement on the Physician/Dentist Assessment Form (PAF)
- Whether or not you have other health insurance (including Medicaid or CHIP)
- How long you have been on the waiting list

Important Note

If you're younger than 19 years of age and a U.S. citizen or legal resident, you must apply for Medicaid or CHIP.

If you've applied within the past 12 months, you must also send in a copy of the most recent determination letter from Medicaid or CHIP. Visit **www.medicaid.gov/chip/index.html** to download an application.

If you haven't applied for CHIP or Medicaid in the past 12 months, you must do so before applying to our program.

BENEFITS AND LIMITATIONS

Our program offers many different kinds of medical and non-medical benefits. This section explains which benefits are covered, which ones are not, and who is responsible for paying for them.

Medical Benefits

Preventative and Specialized Care

Regular checkups with your primary care physician and visits to specialists are covered benefits. You don't need a referral to see a specialist.

Medicines

If you only have drug coverage through our program, we will pay for your medicines at pharmacies that are enrolled in our program. To find a pharmacy near you or to find out if your current pharmacy is enrolled with us, call **800-252-8023** or do an online search at **www.txvendordrug.com**.

If you have coverage under other health insurance, your pharmacy will coordinate payment. In most cases, our program will pay the co-pay.

Other Covered Benefits

- Ambulance
- Outpatient surgery
- Dental health services
- Equipment and medical supplies
- Home health nursing
- Hospice care
- Hospital care
- Immunizations
- Inpatient rehabilitation
- Labs and X-rays
- Mental health services
- Orthotics and prosthetics
- Kidney dialysis
- Special nutritional products and services
- Physical, speech, and occupational therapy
- Speech services
- Vision and hearing services

Benefit Limitations

Some benefits are not covered or are limited. Limitations might depend on your particular case.

Benefits must be medically necessary for the care and treatment for chronic physical or developmental conditions

Prior Authorization

Some benefits require prior authorization. This means that we need to make sure that you are eligible for the service before receiving it. Ask your health care provider to make the request.

We will write to you and your provider approving or denying the service. If you don't agree with our decision to deny the service, you may appeal it. (See page 11 for information on requesting an administrative review).

Finding a Health Care Provider

Providers can include primary care physicians, specialists, hospitals, clinics, and others.

If you already see a provider that is not enrolled in our program, your provider can call **800-568-2413** for application information. Enrollment is quick and easy.

For covered benefits, you must see a health care provider enrolled in our program. Otherwise you'll be responsible for paying the bill.

If you need to see a doctor or health-care provider, use the Online Provider Lookup tool on the Texas Medicaid & Healthcare Partnership (TMHP) website. To use this tool, visit **http://opl.tmhp.com.** Before you do your search, pick **CSHCN Services Program** under **Health Plan**. If you have trouble finding a provider using this tool, dial **877-888-2350** to speak to a TMHP representative.

TMHP has information about our program, like covered services, co-pays, and more. A TMHP representative can also help you with problems or issues that might arise with a provider. For example, if your provider bills you, TMHP will help you. If you receive a bill, see the **FAQ's** section for the steps you need to take.

Non-Medical Benefits

Case Management

Case management involves working one on one with a social worker to help you plan, coordinate, and access available health care and related services for you and your family. As a team, you can improve your health and your family's well-being.

Call your health services office to get an assigned case manager. If you do not know the office number, call 800-252-8023.

Community-Based Services

We contract with many community organizations across Texas to provide you and your family with supports and resources. These include case management, family education, sibling support, and respite. Please note that not all services are available in all parts of the state.

To find support in your area, visit **hhs.texas.gov/services/health/medicaid-chip/about-medicaid-chip/homecommunity-based-services**.

Travel Benefits

Medical Transportation Services

Trouble getting to your doctor's appointments or the pharmacy? If you maintain your eligibility with us, you are able to get medical transportation services. These are rides that you can set up in advance to get to your visits. This service is provided by the Texas Health and Human Services Commission.

The number you call to set up a ride depends on where you live:

- For the Houston / Beaumont area, dial **855-687-4786**.
- For the Dallas area, dial **855-687-3255**.
- Everyone else can call **877-633-8747** (877-MED-TRIP).

If you need help, contact your case manager.

Special Transportation

We might be able to help you with transportation or mileage reimbursement when staying overnight in another city for medical reasons.

If you have an appointment for medical reasons that requires you to stay away from home overnight or longer, we might help with special medical transportation. This might include travel, mileage reimbursement, meals, and lodging. These benefits are reviewed on a case by case basis and must be approved in advance. Contact your case manager to learn more.

Insurance Premium Payment Assistance (IPPA)

IPPA is an insurance premium reimbursement benefit. It is available if the cost of your medical treatment is more than your health insurance premiums. To be eligible for IPPA, you must maintain eligibility with us and have other health coverage—including Medicare and Medicaid Buy-In for Children (MBIC). Children's Health Insurance Program (CHIP) fees are **not** covered.

You don't have to apply for IPPA. If you're eligible, our program or TMHP will contact you and work with you to set up the payment process. You'll have to pay each premium first, but IPPA will pay you back.

NOTE: IPPA coverage is reviewed each year. If you lose our program's eligibility, you will also lose the IPPA benefit.

Language Services

Language services are available at no charge for people with disabilities and people whose primary language is not English. If you need help with language interpretation or translation, talk to your health services office case manager or call **800-252-8023**.

Family Support Services

Family Support Services (FSS) can help you with care at home.

- **Respite care.** This is care provided to relieve a client's primary care giver, including parents. It allows regular providers and care givers to take a short break to refresh and renew.
- **Specialized childcare costs.** These are costs above and beyond the costs for typical childcare, and must be related to disability or medical condition.
- **Vehicle modifications.** These are changes or installations , such as wheelchair lifts and tie-downs, attached ramps, hoists, etc..
- **Minor home modifications.** These are changes in the home such as ramps, roll-in showers, and wider doorways.
- **Specialized equipment that is not a covered benefit in health insurance plans.** These include porch or stair lifts, positioning gear, and bath aids.
- **Counseling, conferences, and training programs**. These help families learn more skills related to care.

Through FSS, clients can become more independent at home or take part in community activities.

FSS Limitations

Funding is limited and might not always be available.

The total costs for FSS cannot be more than $3,600 per calendar year. Exceptions might be made for vehicle modifications which might be up to $7,200 once in a lifetime.

For minor home modifications, families may choose to combine their annual benefit with their one-time benefit of $3,600 for a total of $7,200.

FSS requires prior authorization.

This means that we need to make sure that you are eligible for each service before approving it. Ask your case manager to make the request.

Services Outside of Texas

Within 50 miles of the Texas border

Providers are not considered "out-of-state" if they are located in the United States and within 50 miles of the Texas border (in New Mexico, Oklahoma, Arkansas, or Louisiana). We might be able to cover the cost of these services if:

- It would cost more for you to see a provider in Texas.
- Seeing a provider in Texas would put you at a greater medical risk.

We might cover the costs of transportation, meals, and lodging.

More than 50 miles from the Texas border

Providers are considered to be out-of-state providers if they are located in the United States but are more than 50 miles from the Texas border. Services from out-of-state providers must be approved in advance.

We might cover services if you, the provider, and our program all agree that:

- The out-of-state provider is the provider of choice for quality care.
- The same treatment or another treatment of equal benefit or cost is not available in Texas.
- The out-of-state treatment will cut our program's cost for the treatment.
- The out-of-state treatment is accepted medical practice.
- The out-of-state treatment is likely to improve your quality of life.

We might also be able to cover the costs of transportation, meals, and lodging. Travel costs are negotiated to find the most economical options. Normal authorization requirements and procedures do not apply to out-of-state services because we give these services special approval.

Outside of the United States

We do not cover International services.

YOUR RIGHTS AND RESPONSIBILITIES WITH THE CSHCN SERVICES PROGRAM

Because you're in the CSHCN Services Program, you have certain rights and responsibilities. Every time you reapply for program benefits, you must complete and sign a new application. By doing so, you're agreeing that:

- You have read and understood everything in it.
- All the information you give us is true and complete.
- Holding back requested information or providing information that is not true might result in legal action taken against you.
- You'll let us know of any changes to your application.
- If we overpay you, you must pay us back.

Basic Responsibilities

You have the responsibility to:

- Reapply to our program every 12 months to maintain your eligibility.
- Let us know if you lose your Notice of Eligibility (NOE).
- Always contact your primary health care provider first for your medical needs.
- Understand when you should and should not go the emergency room.
- Work with your provider regarding the best options for your treatment and how to address your health care needs.
- Do everything you can to keep yourself healthy.

Basic Rights

You have the right to:

- Be treated with respect by providers and staff.
- Have your providers keep your personal information private.
- Get copies of medical records from your providers.
- Ask us or your providers questions and get answers about anything you don't understand.
- Have your providers explain your health care needs and discuss different treatment options.
- Make personal choices about your treatment, including rejecting it.
- Get a letter that tells you why services were not given or approved.

- Get a letter that lets you of changes to your eligibility, such as suspension or termination.
- Get a quick response to your complaints.
- Appeal a program decision you do not agree with (see "Your Right to Appeal," below).

Your Right to Appeal

If you or your provider ask for a service and it is not approved, you will receive a letter stating the reasons why the service can't be authorized. Some reasons for denial might include:

- You no longer meet our eligibility requirements, such as: Texas residency, income, aging out of the program, and others
- Your application or other requested information is found intentionally to be incorrect
- You have received payment from a third-party (such as an insurance company) and have not reimbursed us for provided services as required
- You misuse our services
- You are placed back on the waiting list for health care coverage

Whenever you disagree with a decision we make, you have the right to ask for an administrative review (appeal) and fair hearing, and get a timely response to these requests.

Administrative Review

An administrative review is an appeal process for you to present the reasons why you disagree with a specific decision we make. For example, why you believe your eligibility should be approved, or why services you asked for should be authorized.

To ask for an Administrative Review, write us a letter **within 30 days of the date on the denial letter**. You must state why you disagree with our decision and include any documents and proofs you believe support your position.

Send your letter via fax to **512-776-7238** or by mail to:

CSHCN Services Program
Administrative Review, MC 1938
PO Box 149030
Austin, Texas 78714-9947

Fair Hearing

If your administrative review is denied and you are not satisfied with our decision, you have a right to ask for a Fair Hearing.

To ask for a Fair Hearing, write us a letter **within 20 days of the date on the denial letter**. You must state why you disagree with our decision and include any documents and proofs that you believe support your position.

Send your letter via fax to **512-776-7238** or by mail to:

CSHCN Services Program
Fair Hearing, MC 1938
PO Box 149030
Austin, Texas 78714-9947

At the hearing, you may represent yourself or bring a spokesman with you. This can be a family member, a friend, or a lawyer. If you need language interpretation, services are available at no charge.

If you do not ask for a hearing within the required 20-day period, you waive your right to a hearing request and our decision will be final.

THE CSHCN SERVICES PROGRAM & YOUR OTHER HEALTH CARE COVERAGE

This section covers important information for people in the program who also have private insurance or any other health care coverage. This is known as "third-party" coverage.

The CSHCN Services Program is the payer of last resort. That means that if you have any other health care coverage, we can only consider paying for your office visits and services after you've used all other available coverage. If a service is covered by any of the types of coverage listed below, we might not pay for it:

- Private health insurance
- Dental insurance
- Health maintenance organization (HMO)
- Automobile liability insurance
- Preferred provider organization (PPO)
- Cause of action (lawsuit)
- Medicare—Parts A, B, and D
- TRICARE
- Employee welfare plan
- Union health plan
- Children's Health Insurance Program (CHIP)
- Prescription drug insurance
- Vision insurance
- Texas Medicaid Program

You **must** keep your private health insurance, Medicaid, or CHIP coverage active at all times. You have 30 days before you drop your third-party coverage to let us know that you plan to do so. If we find that you no longer have third-party coverage, we'll send you a letter asking you to get it again, if possible.

If you need help paying the premium, we may be able to help you. Read about Insurance Premium Payment Assistance (IPPA) in the **Program Benefits** section.

If you have Medicaid...

Some people in the CSHCN Services Program also have Medicaid coverage, which pays for all or most of the services they need. Because our program is the payer of last resort, we don't pay for:

- A service covered by Medicaid
- A service not covered by Medicaid. If Medicaid denies a service, we can't cover it either.

When visiting your providers, show them the YourTexasBenefits card that Medicaid sends you, and your CSHCN Services Program Notice of Eligibility (NOE).

To learn more about Medicaid, visit **www.medicaid.gov**.

If you have Children's Health Insurance Program (CHIP)...

Our program might provide some services that CHIP does not. However, we cannot pay CHIP premiums or reimburse for CHIP co-pays.

When visiting your providers, show your CHIP identification card and your CSHCN Services Program Notice of Eligibility (NOE).

To learn more about CHIP, visit **www.medicaid.gov/chip/index.html**.

If you have other health insurance...

Some people in the CSHCN Services Program also have other health insurance. Our program covers some services other health care plans do not. If your other health insurance covers a service, we can't pay for it. However, if the full amount billed by your provider to your other health insurance company is not paid, your provider may bill us for what is left over.

When visiting your providers, show your other health insurance documentation and mention that you also have CSHCN Services Program coverage and show your Notice of Eligibility (NOE).

Note: Many health care plans have deadlines and prior authorization requirements for some services. You must meet those requirements to receive services. If a specific service is denied because you or your provider didn't meet the deadlines or requirements, we can't pay for it.

If your private insurance pays for your medicines...

If you have drug coverage through other health insurance, your insurance company must be billed first. In most cases, your pharmacist can then bill our program for your co-pay.

If you have Children's Health Insurance Program (CHIP) coverage, we can't reimburse you for drug co-pays.

If you have a health plan through a community program or clinic...

Some local communities and medical clinics have special health plans that are not considered private insurance. These clinics are not available in all areas in Texas, but you can ask your county hospital or case manager if there is coverage available to you.

We don't require you to use any of these clinics' services first before you can receive our benefits.

FREQUENTLY ASKED QUESTIONS

Are services covered by a provider who is not enrolled in the program?

No. You're only covered if you visit providers who are enrolled in our program. If you would like to get services by a provider that is not enrolled, you can ask the provider to sign up by calling **800-568-2413**.

How do I find a particular specialist in my area?

Use the **Online Provider Lookup** on the Texas Medicaid & Healthcare Partnership (TMHP) website at **http://opl.tmhp.com**. Before you do your search, pick **CSHCN Services Program** under **Health Plan**. If you need help, call **877-888-2350**.

How do I find a case manager?

Call **800-252-8023** and ask for the number of the health services office in your area. If there isn't an office in your city, ask for a call from the regional office, this way you do not have to make a long-distance call.

Are prescription drugs covered?

It depends.

If you only have drug coverage through our program, we fully pay for your medicines.

If you have other health insurance with drug coverage, your pharmacy must bill your insurance company first before billing us for your co-pay.

If you are in the Children's Health Insurance Program (CHIP)**,** we cannot pay for your co-pay.

Do I have travel benefits?

Yes. As long as you maintain your eligibility with us, you're able to get medical transportation services. These are helpful when you don't have a ride to go to an appointment or the pharmacy. You must set up your call in advance and the number you call depends on where you live:

- For the Houston / Beaumont area, dial **855-687-4786**.
- For the Dallas area, dial **855-687-3255**.
- Everyone else can call **877-633-8747** (877-MED-TRIP).

If you have an appointment that requires you to stay away from home overnight or longer, we might help you with special medical transportation services.

To learn more about available transportation, see **Travel Benefits** under the **Non-Medical Benefits** section in this Guide.

Can I go to any pharmacy to get my medicines?

No. Your medicines are only covered at pharmacies that are enrolled in our program. To find a pharmacy near you or find out if your current one is enrolled with us, do a Pharmacy Providers Search at **www.txvendordrug.com/providers**. If you need help finding a pharmacy or have a problem at the pharmacy, call **800-252-8023**.

When should I use my Notice of Eligibility?

Your Notice of Eligibility acts as your client ID. Take it with you each time you go to your doctor's office, clinic, hospital, and the pharmacy where you pick up your medicines. Always let your providers know that you're in the CSHCN Services Program.

Does my Notice of Eligibility expire?

Yes. You must reapply to our program every 12 months. Each time you get approved, you'll get a new Notice of Eligibility. Always use the most current one.

What if I lose my Notice of Eligibility?

If you lose your Notice of Eligibility, call **800-252-8023**. We'll mail you a copy or, with your permission, fax it to your provider's office.

How do I know when to go to the emergency room or an urgent clinic?

There're many things you can do to avoid going to the emergency room or an urgent clinic. First, talk to your doctors about new or persistent symptoms or health problems. Ask when you should come in to the office to be treated, and what the warning signs are for seeking medical attention right away.

Also, find out if your doctors' offices are open late in the afternoon and on the weekends. Save yourself a trip to the emergency room when it would better to visit your doctor. Because your doctor has your medical history, you may be treated faster.

If your doctor's office is closed but you do not have an emergency, go to an urgent care clinic. Many urgent care clinics are open late and have weekend hours. You don't have to call ahead, but make sure it accepts the CSHCN Services Program. It's a good idea to know what urgent care clinics are near you, in case you ever need to get services there.

My provider is billing me for a service. What do I do?

If you get a medical bill, call your provider right away. Do not wait until you get several notices about an unpaid bill. The provider might only need more information or clarification about your CSHCN Services Program benefits.

There are a number of other reasons why a provider might bill you for a service, such as

- You visited an unenrolled provider.
- The service you got was not a covered benefit.
- You were ineligible for our benefits on the date of service.
- You didn't use your Medicaid, CHIP or other health insurance first.
- You didn't follow the policies and guidelines of Medicaid, CHIP, or your other health insurance.
- You didn't let the provider know about restrictions to your other health insurance.

If the provider bills you for a reason that is not listed above, call the Texas Medicaid & Healthcare Partnership (TMHP) at **877-888-2350**. TMHP manages claims for us and will ask you to follow these steps:

1. Make a copy of the bill (keep the original for your records). Make sure that it has the provider's name and address, your name and client ID or social security number, the date of the service, the balance and any payments you made. If you don't have a copy of the bill with this information, ask the provider for a copy of the bill with this information.
2. Write a letter with the date you told the provider you are a CSHCN Services Program client, and the name of person you spoke with at the office if you know it.
3. Send the copy of the bill and your letter to:

Client Correspondence
PO Box 202018
Austin, TX 78720-2018

Expect a response from TMHP within 30 days of date you sent the letter.

If you ever have any provider-related issues, call TMHP for help at **877-888-2350**.

CONTACT INFORMATION

Health Services Regions

We encourage you to work with a case manager at a state health services office for help with your special health care needs. Texas is divided into regions. To find your region, visit **hhs.texas.gov/about-hhs/find-us/community-services-regional-contacts** or call **800-252-8023**.

Useful Numbers

CSHCN Services Program Helpline: 800-252-8023

Call this number if you have any questions about our program, don't have a case manager, need an application, or have changes to your personal or household information. Our phone staff is available Monday through Friday, from 8 a.m. to 5 p.m. Central Time.

TMHP-CSHCN Client Assistance Line **877-888-2350**

CSHCN Services Program Central Office in Austin, TX **512-776-7150**

CSHCN Services Program Fax **512-206-3988**

Medicaid Client Hotline **800-252-8263**

CHIP Call Center ..... **877-543-7669** or **800-647-6558**

Mailing Address

CSHCN Services Program
MC 1938
PO Box 149030
Austin, Texas 78714-9947

Website: hhs.texas.gov/services/disability/children-special-health-care-needs-program

Visit our site regularly to look up general information or look out for the latest news and notices.

Email Help Desk: cshcn@hhs.texas.gov

We make every effort to reply within two business days. If you need immediate help, it is best to call our Helpline or your regional case manager.

2-1-1 Texas

Dial **2-1-1** to find other services in your area or through other state programs. If you cannot connect, call **877-541-7905** toll free or visit the 2-1-1 Texas website at **www.211texas.org** to find the phone number to your local information center.

You might not be able to connect to **2-1-1** if:

- You are calling from outside of Texas.
- Your cell phone will not dial **2-1-1**.
- You use voice-over-IP (use the Internet to make calls)

We may contact you from time to time...

Letters

Occasionally, we might contact you to ask for information or let you know something. For example, you might receive a letter about your application or another form. In such a case, if you don't answer a letter by the due date or don't answer at all, you could lose eligibility or have delays renewing the application. Read all letters carefully and answer them by the due dates.

Our letters always have a phone number in case there is something you don't understand or don't know what to do. Our Helpline staff will help you in every way possible. Please have the letter with you when you call to get help quicker.

You can also ask your state health services case manager for help with the letter.

Surveys

Because we are committed to serving you, and we're always looking for ways to improve our service. One of the best ways is to hear directly from you. So sometimes we send out surveys to better understand our families' needs, concerns, and strengths in caring and meeting their special health care needs. If you get an invitation to complete a survey, we encourage you to give us input. This is a great way for you to share your experiences and opinions to help us improve services and customer service for everyone in our program.

THE MEDICAL HOME

A medical home is not a building or a place. A medical home is care team made up by your doctors and nurses, therapists, dentists, and pharmacists. Your team can also include your community health workers, school staff, friends, neighbors, and anyone else who cares for you.

Having a medical home care team lets your family work with health care experts to find and get both the medical and non-medical services you need. A medical home can improve your health and make life easier for your family.

You deserve a medical team that is:

- **Accessible:** Care is provided for you in your community 24 hours a day, 7 days a week.
- **Family-Centered:** Your family is recognized as an expert on you, and are all valued members of the care team.
- **Continuous:** The same pediatric health care professionals care from infancy until it's time to transition to adult care.
- **Comprehensive:** Your care plan includes checkups, sick visits, therapy, and specialty care. Your family is connected to support and educational services.
- **Coordinated:** Your team works with your providers to make a care plan, book appointments, handle referrals, and get access to resources.
- **Compassionate:** Your care team is genuinely concerned about the overall well-being of your child and family.
- **Culturally Effective:** Your care team respects your family's cultural and religious beliefs. You get services in your preferred language.

What if I do not have a medical home?

Here are a few ways to begin building your medical home:

1. **Choose a primary care physician you trust.** Your main doctor or specialist should coordinate the full range of services you need and should value you as a partner in your care.
2. **Make a written care plan.** Work with your main doctor to write a plan that addresses your needs and goals. Make sure that it is shared with the entire care team and gets updated regularly.
3. **Create a care notebook.** Keep a binder to organize important information about appointments, therapies, and medical summary with your current and past medications, any allergies, etc. The notebook allows you to keep track your health information and manage your care and treatment. Take it with you to all your appointments to allow your providers learn about your health care history and current status quickly and accurately.

4. **Ask questions and communicate.** Your family is your best advocate. Take all your questions, concerns, and observations to each appointment. Always let providers know if there is something you don't understand or need more or other help. Get to know everyone in your medical home, including your doctor's staff.

To learn more on the medical home visit:

- Navigate Life Texas at **navigatelifetexas.org**
- Texas Parent to Parent at **www.txp2p.org**
- CSHCN Services Program at **hhs.texas.gov/services/disability/children-special-health-care-needs-program**

"Our medical home is a place where they know my story, they listen to my son, and they respect us. They help us get services that go beyond medicine. They talk to us."

— Judie W,
whose 18-year old son has cerebral palsy and asthma.

Transition Planning

A medical home should include a plan for youth with special health care needs to transition into adulthood. Finding a provider for adult care is one of the most important steps. But planning for adulthood can also include:

- Deciding where to live, work, or play
- Knowing what legal changes will need to be addressed
- Finding out what services will be available
- Deciding how these services will be paid for as an adult

Thinking about all of these changes can seem overwhelming. But starting early can make a big difference. Transition planning can begin as early as age 12. A good medical home and ongoing planning can help ensure a successful transition into adulthood.

Transition Toolkit

The toolkit has a list of many statewide resources for young adults. There are many different categories, like special education, health care safety considerations, housing "how-to," financial and legal aid, and social and recreational programs.

Remember, you are not alone! Contact your medical home team or local case manager to go over your needs, and set goals and start a **transition plan**. Seek out others who have already moved to adult care for help and guidance.

EMERGENCY AND DISASTER PREPAREDNESS

The CSHCN Services Program encourages all families to plan and prepare for disasters and other emergencies.

Disasters can strike quickly and without warning. Because you and your loved ones could be anywhere when a disaster happens—at work, at school, or in the car—it is very important to know what types of emergencies are likely to affect your area *before* they happen.

Make a plan.

Planning with your family for an emergency is critical and the best way to protect everyone's safety. Each family needs a personalized emergency plan and kit. Talk to everyone in your family about what to do and which steps to take should a disaster happen.

Build a kit.

- ☐ Learn how to collect and store important information and supplies for your emergency kit. Record birthdates, work and school addressees, emergency contacts and medical information.
- ☐ Record diagnoses, current medications, allergies, immunization history, and past procedures. The form provides essential health information about you to responders in an emergency.
- ☐ Record all your current medications and non-prescription medications (like pain killers, vitamins and supplements).
- ☐ Print the **Disaster Supply Checklist** from **www.texasready.gov**. Use it to build your kit step by step. Consider essential supplies, medicines and other assistance each of your family members needs for at least three days. Make sure you build it to shelter in place or evacuate.
- ☐ Keep your important personal documents dry in a re-sealable plastic bag. If possible, keep copies of the forms in your backpack and at locations you frequent like your school office, daycare, or with a family member.
- ☐ Take your documents to your appointments or visits to the hospital. Have your providers help you update your medications, dosage, reasons for treatment, and other prescribing doctors. Having updated forms with you is a crucial during a disaster.

For more information, visit:

- **www.texasready.gov**

FINDING HELP IN TEXAS

Many families struggle to find help. It can be stressful and overwhelming not knowing where to go or what to do. But Texas families are not alone. Texas has useful resources and available services statewide.

Use the resources below to find the help you need. We encourage you to spend some time learning about each one and the services that are offered.

2-1-1 Texas

www.211texas.org

2-1-1 Texas is a social service hotline, and an easy way to look up services and resources for your family. Whether you need help finding food or housing, child care, crisis counseling or substance abuse treatment, one phone number is all you need to know.

No matter where you live in Texas, simply dial **2-1-1**. If you cannot connect, call **877-541-7905** or visit the website. It is a free, anonymous line available 24 hours a day, 7 days a week, 365 days a year.

Navigate Life Texas

www.navigatelifetexas.org

A full service, user-friendly website with resources ranging from family supports to financial help and how to talk to your doctor. There is also access to help with

- Self-care, day care, and respite
- Special education and transitioning between schools
- Planning for transitioning to adulthood
- Teenagers and risky behavior
- ...and much more

"I wish I had this five years ago when we were starting out."

— A parent navigating the NLT website

You can easily look up condition definitions, risk factors, complications, and treatments using the A-Z diagnosis list. There is also information for children with multiple, rare, or undiagnosed conditions.

Families like yours have helped create this website to empower other families with similar special health care needs. You'll be surprised how many parents and caregivers understand your struggles and can help you find support!

Texas Parent to Parent (TxP2P)

www.txp2p.org

A parent-to parent peer support network advocating for families with children with chronic illness and special health care needs. TxP2P looks to improve the health care and well-being of children around the state through family-centered tools, information, and support groups.