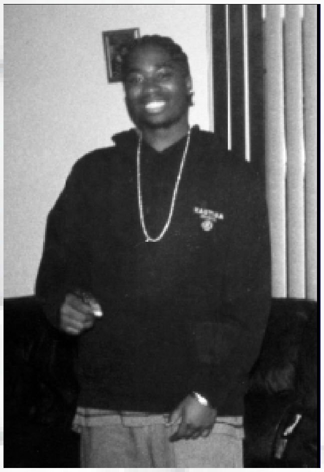
FAMILY GUIDE

To Michigan's Children's Special Health Care Services Program



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STATE OF MICHIGAN
DEPARTMENT OF COMMUNITY HEALTH
LANSING

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Children's Special Health Care Services (CSHCS) is a program of the Michigan Department of Community Health (MDCH). CSHCS helps children and some adults who need specialty medical care. Specialty medical care is care that cannot be managed only by pediatricians, family doctors or internists.

CSHCS is part of state government, and so it belongs to families. This *Family Guide* explains how CSHCS works. It tells you how to get help from us.

Many parents find it overwhelming and confusing to suddenly need CSHCS. However, lots of help is available to sort out the system. We hope that the information in this book will help you. If you like to go on the Internet, you may click to free courses, about Children's Special Health Care Services and a support parent training, at www.training.mihealth.org

Many persons tell us that they appreciate talking to a "live person." Knowledgeable persons answer the CSHCS Family Phone Line at 1-800-359-3722. They can transfer you toll-free to any CSHCS provider, CSHCS office, or your local health department. CSHCS representatives in your local health department are ready to help you. If needed, an over-the-phone translator is available so that you may use the language you prefer.

This *Family Guide* also tells you how to get help from others. We can connect you to a parent support group in your community. We can match you one-to-one with a fellow parent of a child with special needs. You'll find a long list of resources starting on page 46.

Parents wrote this *Family Guide* just for you. There's no need to read it cover-to-cover in one sitting. Just look up information as you need it.

Sincerely,

Mary J. Marin

Mary J. Marin,
Executive Director, Family Center,
Children's Special Health Care Services

"Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support….A family is a culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity…Our families create neighborhoods, communities, states and nations."

From the 1990 Report of the New Mexico House memorial 5 Task Force on Young Children and Families

Table of Contents

The CSHCS Approach to Services

CSHCS provides:

- Coverage and referral for specialty services, based on the medical condition
- Family-centered services, including parent-to-parent support
- Community-based services
- Cultural services that recognize cultural differences or needs
- Coordinated care that pulls together services of many providers who work within different agencies

Medical Home

Michigan and other states across the nation are aiming to fulfill the national Healthy People 2010 public health objectives. One is to assure access to a medical home for children with special health needs. Read details at an American Academy of Pediatrics website: www.medicalhomeinfo.org.

A medical Home is not a place or location; it is a way your physician should provide care that is:

Accessible

Care is provided in the child's community

Family-centered

Recognition that the family is the principal caregiver and the center of strength and support for children

Continuous

Some suggests we cover primary pediatric health care professionals who are available from infancy through adolescence

Comprehensive

Healthcare is available 24 hours a day, seven days a week

Coordinated - The medical home refers and communicates with other doctors

Families are linked to support, educational and community-based services

Compassionate

Concern for the well being of the child and family is expressed and demonstrated

Culturally competent

Family's cultural background is recognized, valued and respected

Source: *What Is A Medical Home? And What Does It Mean For You and Your Child?* University of Illinois at Chicago, Division of Specialized Care for Children, publication 40.16, 2003.

Information & Resources

CSHCS information and emotional support for parents are available to all Michigan families of children with special needs. Enrollment in CSHCS is not required to access the following resources:

- Family Center
- CSHCS Family Phone Line
- Parent-to-Parent Support
- Conference Scholarships
- Children with Special Needs Fund
- Relatively Speaking Conference

The Family Center for Children & Youth with Special Needs (FC), a section of CSHCS, gives parents a voice in CSHCS programs and policy making. Most Family Center staff members are parents of children with special health needs. They and other parents of children with special health needs have formal roles in CSHCS. FC staff also run the Family Support Network of Michigan and administers parent conference Scholarships and conference scholarships for youth and young adults with special needs.

CSHCS Family Phone Line operators help families understand and navigate the CSHCS process. By calling 1-800-359-3722, families can get answers to questions such as:

- Has my child been found eligible for CSHCS?
- Has the medical report been received?

The phone line staff also helps families find general information concerning children with special needs. Families who do not speak English may ask for an on-the-phone interpreter when they call. Families can be transferred toll-free to any CSHCS office.

Parent to Parent Tip!

One thing parents always recommend to other parents of children with special needs is to stay organized. A really great tool for organizing care is an individual care plan. Your care coordinator may refer to this as a "Plan of Care." Your care coordinator can help you develop a written care plan. Typically, it lists the member's:

- health problems,
- upcoming tests or procedures,
- providers,
- health care services and equipment, and
- treatment plan with expected outcomes.
- Education, social and community resources.

You also may want your care plan to note what is covered by Medicaid or by your private health insurer.

You can use the care plan to keep track of all of your providers. It's a good idea to share copies with your doctors so they each have a full picture of your child's treatment. Keep a copy with you when you go to the hospital or to a new provider to make the admission or intake interview easier.

To get started, think about the questions below:

- Do you need more information about your or your child's medical condition or treatment?
- Which specialists will you or your child see?
- Are the specialists already CSHCS-approved providers? If not, what are your options?
- What therapies are needed?
- What prescription medications do you or your child use?
- Is equipment needed, such as a wheelchair, braces, oxygen, etc?
- Do you need help with transportation to medical appointments?
- Is surgery a possibility?
- Do you have a plan for emergency care?
- Are medical or health services needed at school?
- Do you need medical documentation for an Individualized Education Plan (IEP) meeting?
- Does a caregiver need training for any medical treatment to be given?
- Do you need CPR training?
- Would you like to speak to another parent of a child or youth with special health care needs?

Information & Resources

Who Should Use the CSHCS Family Phone Line?

The CSHCS Family Phone Line is only for parents, guardians, and clients use, by calling 1-800-359-3722 to:

- Call the CSHCS office in any local health department
- Make a call to CSHCS staff in the Lansing office
- Obtain general information on how to join CSHCS
- Resolve problems related to CSHCS
- Contact their CSHCS medical provider(s)
- Contact the Family Support Network of Michigan
- Reach their FSN Support Parent for up to 30 minutes

Note: We are not funded to transfer callers to other agencies such as Community Mental Health, the Department of Human Services, schools, Intermediate School Districts (ISDs) Head Start Offices, Friend of the Court, and other court offices

Information & Resources

CSHCS's parent-to-parent support arm is the ***Family Support Network of Michigan*** **(FSN)**. It is open to all families who have children with special needs. FSN helps families come together for information and emotional support. FSN provides:

- Parent support groups
- One-to-one support by trained volunteer parents
- Information about programs for brothers, sisters, mothers, fathers, and grandparents
- Family social events
- Information about local, state, and national resources

Michigan families can apply for a ***conference scholarship*** to help cover expenses for one parent to attend a conference related to their child's specialty diagnosis, condition or treatment. Families applying for the first time have priority. CSHCS covered clients, age 16 and above, can also apply for conference scholarships.

The ***Children with Special Needs Fund*** provides services and equipment to children with special health care needs that no other resource – including state or federal programs – provides. For medically eligible recipients, the Fund may provide partial or full funding, while the funding remains available, for items such as:

- Wheelchair ramps into homes
- Van lifts and tie downs
- Therapeutic tricycles
- Air conditioners
- Adaptive recreational equipment
- Electrical service upgrades necessitated by the eligible child's equipment
- Camp scholarships

Relatively Speaking is a weekend conference funded by the Children with Special Needs Fund and sponsored by the Family Center. The event is specially designed to address the special issues of young brothers and sisters of children with special needs. The conference is held every other year.

Additional FC resources include a ***Heart-to-Heart Information Update*** about CSHCS issues and other information of interest to families of children with special needs. It is mailed to families upon request, at no charge.

Community Resources

A long list of agencies ready to help families starts on page 46.

CSHCS Eligibility

Medical condition plus three other factors decide whether a person is eligible for CSHCS:

1. Residency

A person must be a Michigan resident to receive CSHCS. A resident is defined as a person who lives in Michigan and plans to reside in Michigan for a period of time or is in Michigan to work or look for a job.

2. Citizenship

U.S. citizens and some non-citizens may qualify for CSHCS coverage. If a non-citizen qualifies for and uses CSHCS, that will not affect his or her chances of receiving a green card. Citizenship restrictions do not apply to migrant worker families.

3. Age

CSHCS covers persons under age 21. The age limit is waived for persons with certain blood clotting disorders or cystic fibrosis.

Myths

It is important to note that financial factors do not count in determining CSHCS eligibility. Many incorrectly believe that CSHCS is for families with little or no income. In fact, families at every income level are in the CSHCS program.

It is a myth that families with private health insurance are not eligible. The parents of many children with CSHCS coverage have private health insurance. CSHCS provides additional help to those families.

CSHCS covers over 2,600 health conditions. They include:

- Chronic conditions peculiar to newborns, such as respiratory distress syndrome and apnea
- Congenital anomalies
- Diseases of the blood and blood-forming organs
- Diseases of the circulatory, respiratory, digestive, and genitourinary systems
- Diseases of the nervous system and the sense organs
- Diseases of the skin and subcutaneous tissue, musculoskeletal and connective tissue
- Endocrine, nutritional and metabolic diseases
- Infectious and parasitic diseases
- Late effects of injuries and poisonings
- Neoplasm

This list does not cover every possibility.

If you *think* that you or your child qualifies for CSHCS, call our toll-free Family Phone Line at 1-800-359-3722. We will transfer you to your local health department for help. MDCH is committed to finding and caring for all people eligible for CSHCS. In some cases, MDCH will pay for an evaluation to determine medical eligibility.

Examples of medically eligible conditions are:

- Cerebral Palsy
- Sensoneural Hearing Loss
- Asthma, if moderate, persistent, or severe
- Diabetes
- Convulsive Epilepsy
- Respiratory Distress Syndrome
- Sickle Cell Disease
- Cleft Lip and Palate
- Congenital Quadriplegia
- Anomalies of Skull/Face bones

Four factors determine whether a condition is covered by CSHCS:

√ Diagnosis
√ Chronicity
√ Severity
√ Need for treatment by a physician specialist

It is important to note that severity is always taken into account. Based on severity, some persons will receive CSHCS coverage for certain conditions while others will not.

How Do I Apply?

To apply, the first step is to have your specialist send us a medical report This information can be in the form of a letter or office records that describe the condition and treatment plan. Or, it can be a completed Medical Eligibility Report Form (MERF). A specialist also may complete a downloadable copy of a MERF, (MSA 4114) at www.michigan.gov/CSHCS Provider Information.

Mail it to: MDCH/CSHCS, P.O. Box 30479, Lansing, MI 48909-8234
Fax: 1-517-335-9491

Next, a CSHCS medical doctor will review the medical report to determine medical eligibility.

If you do not have a specialist, but *think* that you or your child has a condition that may qualify for CSHCS coverage, call a CSHCS representative in your local health department. He or she may be able to help you set up a diagnostic exam, at no cost to you.

- Families who are found medically eligible receive an application packet. Help with filling out the application is available from a CSHCS representative in your local health department. You may choose face-to-face or phone assistance.

How Do I Get Care

- The enrolled person or a family member arranges services with each specialty provider. Or, families may get help from a CSHCS representative in your local health department to coordinate care. Providers must be Medicaid-enrolled and be authorized by CSHCS.

When you have CSHCS coverage, you must:

- go to a provider listed on your Eligibility Notice. The Notice is a letter you receive by mail. It lists the CSHCS member's name, identification (ID) number, start and end dates for coverage, approved providers* and eligible diagnosis. If there is more than one eligible diagnosis, each is listed. To add a person or company to your list of covered providers, call your local health department. A CSHCS representative there can help you.
- take your **mihealth** (spoken "my health") **card** to every appointment. Each person enrolled in CSHCS receives a mihealth card. It is a permanent plastic health benefits identification card. It shows your name and ID number on the front. Tell us right away if your card is lost or stolen. Call 1-800-642-3195 to get a new card.

  Having a mihealth card does not guarantee eligibility. Providers with compatible equipment must swipe the card or call to check your eligibility information. Providers need to know you have CSHCS in order to know what is covered for you.
- show your mihealth card and *Eligibility Notice* to each provider before you receive services. If you don't show your mihealth card, you may have to pay for the service. If you receive a service before showing your mihealth card, the
- provider does not have to accept CSHCS coverage. When CSHCS coverage is not accepted, your family must pay the bill.
- if you have other health insurance, tell the provider. Health insurance must be billed first. You must follow the rules of the insurer before CSHCS will pay.

*The Eligibility Notice lists doctors, hospitals and other providers we cover. Some providers, such as pharmacies, medical equipment and supply companies, hearing and speech centers, hearing aid dealers and home health agencies, are not listed but are approved. Double check the services CSHCS will cover with a CSHCS representative in your local health department.

Services

CSHCS provides a wide range of health services to meet a family's special needs.

Medical Care and Treatment

CSHCS only covers medical services or treatments directly related to the member's eligible diagnosis(es). What is covered depends on the member's medical condition or family circumstances. Based on individual medical needs, services covered **may** include:

- Hearing aids
- Dental/orthodontia
- Vision
- Office visits
- Hospital stays
- Pharmacy
- Genetic counseling
- Laboratory tests
- Occupational therapy
- Physical therapy
- Speech/language therapy
- X-rays, scans, Magnetic resonance imaging (MRI)
- Medical equipment and supplies

Hearing

CSHCS covers medical and audiological treatment to restore a child's hearing or to improve the ability to hear. When needed, treatment may include most types of hearing aids. At this time, we do not cover assistive devices, such as vibrotactile units, auditory trainers, combined hearing aids/FM units. Digital/Programmable hearing aids are a benefit for members under age 21 only when the digital/programmable aid shows superior performance over a conventional analog hearing aid.

Children with hearing loss may get hearing therapy instead of speech-language therapy. The purpose is to make sure that children learn to use hearing aids to the maximum benefit. Cochlear implants are covered for children who meet severity criteria.

Dental

We do not cover dental services for most conditions. We approve *specialty* dental services for a few conditions. Those include cleft palate, cleft lip and some other severe disorders involving teeth. When medically warranted, we may pay for orthodontia before or after surgery.

Services

Vision

CSHCS offers specialty medical or surgical eye care. Conditions we cover include glaucoma, retinal disorders, cataracts, and keratitis. For some children we also may cover eye movement or eye muscle disorders. We do not pay for eyeglasses needed for near- or far-sightedness or astigmatism.

Therapies

We may cover physical, occupational, and speech therapy related to a member's eligible diagnosis. Locations include outpatient hospitals, comprehensive outpatient facilities, and rehabilitation agencies. In all cases, the provider must be properly credentialed.

Occasionally there is a unique reason that therapy needs to take place at the member's home. In that case, CSHCS doctors will review requests from specialists for occupational therapy or physical therapy to be provided at a member's home. The therapy must relate to a member's CSHCS-eligible diagnosis. It must prevent, correct, or compensate for a specific medical problem. A CSHCS-authorized doctor on your list must order the home therapy and a doctor who works at CSHCS must approve it.

Hospital Stays

CSHCS covers specialty medical and surgical care and treatment at CSHCS-approved hospitals. The care must relate to the member's eligible diagnosis. Approved hospitals are listed on the member's Eligibility Notice. To add a provider, check with a CSHCS representative in your local health department. While a CSHCS member is in a hospital away from home, CSHCS also may help with some of the family's travel costs. See below for details.

Transportation Expenses

Help with some medical transportation expenses is a benefit for some CSHCS members. Covered expenses include mileage, lodging, tolls, and parking. To qualify, the transportation must be for care related to the member's CSHCS eligible diagnosis.

Also, the travel must be approved in advance by the CSHCS office in your local health department. Families who need help to pay for medical travel should contact the CSHCS office in your local health department. If your child has Medicaid use Department of Human Services (DHS) travel.

Care Coordination

Some of the people involved with your child include his or her teacher, doctor, nurse, pharmacist or therapist. Your child benefits when everyone works together. Your local health department works with you throughout the year to make sure that your child is receiving all of the services he or she needs. Your nurse might meet with you once a year to review all of your child's needs and providers. You and your nurse will then make a written plan to help everyone work together. This is called a plan of care. With your permission, this plan of care is sent to your child's primary care provider. These activities are called CSHCS care coordination. Some families will need to meet with their nurse more often.

This meeting is usually in your home but could also be in a place that you choose, such as your child's school. This is called CSHCS case management.

Pharmacy

CSHCS covers prescription drugs for a member's eligible diagnosis. We generally do not cover vitamins, over-the-counter medicines, and birth control pills. Families sometimes have questions about pharmacy. An example is that a pharmacy cannot find a CSHCS member in its system. Another example is that a pharmacy's system does not show coverage for a prescription written by a CSHCS-approved doctor. Families can call 1-877-681-7540. Local Health Departments (LHD) can help families solve CSHCS pharmacy problems.

Other Professional Services

CSHCS may cover other services that relate to the member's eligible diagnosis:

- Genetic counseling
- Laboratory tests
- X-rays

Medical Equipment and Supplies

Equipment and supplies CSHCS may cover include:

- Adaptive toilet seats
- Apnea monitors
- Artificial limbs
- Braces (non-dental)
- Corrective shoes
- Eyeglasses/contacts
- Feeding tube/pump
- Hearing aids/batteries
- Hospital beds
- Incontinence supplies
- IV poles
- IV therapy/TPN
- Lifts for bed or bath
- Medical supplies (feeding tubes, catheters, ostomy and tracheotomy supplies, oxygen, special feeding formulas and, syringes)
- Suction and breathing machines
- Walkers, canes, and crutches
- Wheelchairs/adaptive strollers

Check with a CSHCS representative in your local health department for services and equipment CSHCS may cover. When the equipment is not routine, ask your specialist doctor to write a letter to explain the need.

Services

Incontinence Supplies

Supplies can include disposable diapers for members over age three. All incontinence items for which CSHCS will pay must relate to the eligible diagnosis. A doctor's prescription must list each item, such as:

Incontinence catheters and accessories

- Irrigation syringes
- Skin barriers
- Underpads
- Incontinence pants
- Incontinence liners
- Pull-on briefs
- Enema units
- Disposable diapers

For incontinence supplies, there is only one CSHCS-approved provider. J&B Medical has a contract to supply the items listed above. To order, call J&B Medical at 1-800-737-0045. Once approved, Federal Express will deliver incontinence supplies to your home once a month. If your supplies may not last until the next delivery date, you may call-in an emergency order to J & B.

If your address changes, you must let J & B know. To avoid missing a shipment, give your new address at least ten days prior to your delivery date.

Note: Federal Express does not deliver to Post Office (P.O.) boxes. If your mailing address is a P.O. box, you must give J&B a street address for your deliveries.

Out-of-State Care

In special cases CSHCS may approve out-of-state care. To talk about a need, call a CSHCS representative in your local health department. CSHCS must approve out-of-state care in advance.

CSHCS may approve out-of-state care if the treatment needed is not available in Michigan. A CSHCS doctor must approve such care.

In most cases, we need a statement from one of your CSHCS-approved specialists in Michigan saying that the service is not available in Michigan.

CSHCS also needs a medical report that includes a treatment plan for the proposed out-of-state care. If the member needs a return visit, CSHCS must approve it in advance.

We may help to reimburse related transportation, and lodging costs for the patient and one parent or legal guardian. Receipts for certain expenses and a Client Transportation Authorization and Invoice form must be turned in to CSHCS within 90 days of the trip.

Please note that special billing rules apply. Out-of-state providers who do not accept Medicaid billing can bill families for medical care. Even if a provider chooses to bill CSHCS, your family still may have to

pay if we do not cover the service. Or, you may have to pay the portion that is left after CSHCS pays the covered amount.

Medical Care at Home

CSHCS covers several types of specialty care for medically eligible members in their homes. A partial list follows. To apply for services, talk to a CSHCS representative in your local health department.

Private Duty Nursing

Some families continue hospital care at home with the help of a nurse. This is not a CSHCS benefit. The beneficiary must have Medicaid. Examples are using a ventilator and suctioning a tracheostomy tube. Some families deal with highly technical machines.

Children with these kinds of needs who also have Medicaid coverage may qualify for Medicaid's Private Duty Nursing (PDN) benefit. If you think you will need the help of a nurse on a regular basis, talk with your local health department about resources for PDN or other supports.

Visiting Nurses

Some members occasionally need the help of a registered nurse to successfully make a transition from hospital to home. In other cases, a family member needs home care training or information from a nurse.

How often a nurse visits depends on a person's needs. The visits are called Intermittent Skilled Nursing Visits. A CSHCS-approved doctor must order them. Frequency can range from several times each week to a few times each month.

Respite Nursing Care

Families need breaks from giving 24-hour special care without the aid of a nurse. But handling technical care is beyond the skills of most babysitters. Therefore, when you need respite, CSHCS may be able to help. Our Respite Nursing benefit gives families temporary relief from care giving. It is for families who do not have other home nursing services or other resources.

You may get up to 180 hours of home care per eligibility year. Your child's care must need a nurse's skills, such as assessment, judgments and interventions. An approved Registered Nurse or Licensed Practical Nurse must give the care.

To apply, ask a CSHCS representative in your local health department for help with filling out an *Application for Periodic Respite Service for Children with Nursing Care Needs*. If your child is in a hospital, and is being discharged, your discharge planner may fill out the form for you.

Hospice Care

CSHCS may cover supportive end-of-life care for members who are terminally ill. To discuss family needs, contact a CSHCS representative in your local health department.

Services

Health Insurance Premiums & COBRA

In certain cases, CSHCS has a benefit that can pay for all or part of health insurance premiums when families cannot afford to pay

CSHCS may pay a premium when:

- There is an opportunity for health coverage under COBRA.
- There is access to private health insurance and the family cannot afford the premium.

For help, contact a CSHCS representative in your local health department.

Emergency Health Care

Emergency rooms are for serious medical conditions **only**.

The program rules are:

- CSHCS covers emergency care only for CSHCS-eligible conditions.
- An emergency exists if a prudent lay person reasonably believes that having a person wait to be treated by a Medicaid provider will worsen the person's condition.
- A *medical emergency* is "a condition where delay in treatment may result in the person's death or permanent impairment of the person's health."

Emergency Room Care

When emergency room treatment related to the CSHCS-eligible condition is given, notify a CSHCS representative in your local health department as soon as possible. For CSHCS to pay for a visit, the hospital or provider must be on your Eligibility Notice for the date of service.

If the emergency room visit is for routine care unrelated to the CSHCS-eligible condition, you might have to pay the bill.

CSHCS may cover emergency care in and outside of Michigan.

Ambulance Transportation

CSHCS only covers ambulance service related to the eligible diagnosis. If an ambulance is needed for non-emergency transport, CSHCS must approve use in advance. When an ambulance is used in an emergency related to the eligible condition, CSHCS may pay for it. In either case, you must add ambulance service to the Eligibility Notice for the date of service. To do that, call a CSHCS representative in your local health department.

When Do I Have To Pay For CSHCS Services?

If you have coverage from Medicaid, MIChild, or the Women, Infants and Children (WIC) program, you will not pay anything for CSHCS coverage.

Otherwise, Michigan's Public Health Code requires us to consider the ability of families to contribute to the cost of their CSHCS care. A financial assessment is part of the application process. If you agree to pay part of the cost of your CSHCS coverage, you will sign a CSHCS Income Review/Payent Agreement. You will receive 12 monthly payment coupons.

Always show your mihealth card to a provider **before** receiving CSHCS services. **Do not pay any provider for any CSHCS service or supplies**. If you make a mistake and pay a provider directly for CSHCS services, CSHCS does not have a way to reimburse you. Your Eligibility Notice lists doctors, hospitals and other providers we cover. Some providers, such as pharmacies, are not listed but are approved. Double check the services CSHCS will cover with a CSHCS representative in your local health department.

In rare cases, CSHCS-approved doctors, pharmacies, hospitals or other providers may offer a service that CSHCS does not cover. When that happens, CSHCS requires the provider to tell you of your payment responsibility before giving the service.

If you have other health insurance, please note that it needs to be billed first. You must always follow the rules of your other Insurance. By law, CSHCS is the "payer of last resort." That means, CSHCS coverage is always secondary to insurance.

CSHCS can help coordinate insurance benefits. In special cases, such as "COBRA," CSHCS may pay a portion of a member's health insurance premium.

What Services are not Covered by CSHCS?

Primary Care

CSHCS does not cover primary care. That means we don't cover well-baby visits or short-term conditions like common colds or sprained ankles. We only pay for treatment related to the CSHCS member's eligible condition.

To find primary care, talk with the CSHCS office in your local health department. If your income qualifies, your family may get primary care through Medicaid or MIChild. Private health insurance usually includes primary care.

Well-Child Care

CSHCS does not cover well-child care. Families should check for well-child care under your private healthplan, Medicaid or MIChild coverage.

Medicaid and MIChild cover free health checkups. A checkup can find problems you may not know about, such as lead poisoning or hearing or vision problems. Early treatment may prevent you or your children from getting really sick later.

Mental Health Care

CSHCS does not cover mental health diagnoses. A person could have a mental disability plus some other medical problem and be eligible for CSHCS. For example, a child with Down syndrome may be covered by CSHCS for a heart condition.

Services may be available through MDCH's Community Mental Health Division for emotional and behavioral disorders, attention disorders, developmental delays, mental retardation and autism

Experimental Health Care

CSHCS does not pay for experimental treatments or procedures.

Rights & Responsibilities

Your CSHCS Rights and Responsibilities

It is important that you know your rights and responsibilities. In CSHCS, you have the right to:

- Receive quality health care.
- Be treated with respect.
- Choose your specialist.
- Be seen by a medical specialist who will arrange the care you need.
- Get all the facts from your specialist about the CSHCS-eligible diagnosis and treatment.
- Say "no" to any medical treatment.
- Tell the specialist how to treat you or your child if you become too ill to decide for yourself.
- Get a second opinion from a specialist.
- Be told what services CSHCS covers.
- Know the names and backgrounds of your health care providers.
- Get help with any special disability needs you may have.
- Get help with any special language needs you may have.
- Have your medical records kept confidential.
- Get a copy of your medical records.
- Voice your concern about the service or care you receive.
- Be told in writing when and why benefits are being reduced or stopped.
- Contact the Michigan Department of Community Health with any questions or complaints.
- Appeal any denial or reduction of CSHCS eligibility or service.

Rights & Responsibilities

Your Responsibilities:

- Show your mihealth card and *Eligibility Notice* to all providers **before** receiving services.
- Call your local CSHCS office **before** your appointment when you need help to cover medical travel expenses.
- Never let anyone who is not covered use your CSHCS coverage.
- Choose a specialist. Then contact and build a relationship with the provider you have chosen.
- Follow your provider's medical advice.
- Keep your scheduled appointments.
- Provide complete information about past medical history.
- Provide complete information about current medical problems.
- Update medical and financial information as CSHCS requires.
- Ask questions about the care.
- Respect the rights of other patients and health care employees.
- Use emergency room services only when you believe an injury or illness could result in lasting injury or death.
- Notify a CSHCS representative in your local health department if emergency room treatment related to the CSHCS-eligible diagnosis is given.
- Make prompt payment for services not covered by CSHCS.
- Report changes that may affect your coverage to a CSHCS representative in your local health department. This could be an address change, birth of a child, death, marriage, divorce or change in insurance coverage.
- Promptly apply for Medicaid, Medicare, or other insurance when you are eligible.
- Report Medicare, Medicaid, or other insurance benefits you have

Rights & Responsibilities

Complaints and Appeals

If you have complaints or concerns with your CSHCS health care or your CSHCS provider, there are things you can do:

1. Call or write the Department of Community Health (DCH) about your complaint:

   Department of Community Health
   Administrative, Tribunal and Appeals Division
   PO Box 30763
   Lansing MI 48909-7695
   1-877-833-0870

Appealing an Action if CSHCS Denies Coverage or Services, you Can

2. Appeal a negative action, such as CSHCS not paying a bill or not approving a service Complete the form you received when you were notified of the decision. Your request must explain the problem in writing.

   Mail the form to:

   Department of Community Health
   Administrative Tribunal and Appeals Division
   PO Box 30763
   Lansing, Michigan 48909-7695

If you have questions, call the CSHCS Family Phone Line at 1-800-359-3722.

Frequently Asked Questions

CSHCS helps pay for medical care and treatment for certain eligible medical conditions. Families receive a Client Eligibility Notice that lists the begin and end dates for coverage plus certain providers who are authorized to provide services. Families also receive a plastic **mihealth card** for the CSHCS member.

Q. Should I keep the Eligibility Notice?

A. Yes. Your Eligibility Notice works like a health insurance card. You must show it at the doctor's office before you receive service from a CSHCS provider. You will receive a new Notice when there are any changes.

If you do not show your Eligibility Notice until after a provider serves you, the provider does not have to accept CSHCS coverage. When CSHCS coverage is not accepted, your family must pay the bill.

Q. How do I use the mihealth card?

A. Show it at the doctor's office with your Eligibility Notice.

Q. What is covered?

A. CSHCS only pays for treatment related to the member's eligible diagnosis. It does not cover primary care. That means we don't cover well-baby visits or short-term conditions like a cold or sprained ankle.

Q. What if I'm not sure what medical conditions are covered?

A. Call your local CSHCS office or the CSHCS Family Phone Line.

Q. What if I want to go to a provider not listed on the Eligibility Notice?

A. Call your local CSHCS office to see if the provider can be authorized. Without authorization, you may be responsible for the bill.

NOTE: Pharmacies, medical equipment and supply companies, hearing and speech centers, hearing aid dealers, and home health agencies do not have to be listed on the Eligibility Notice.

Q. What if I have bills from services before my coverage's begin date?

A. In some situations, past services related to the eligible diagnosis may be covered. Call your local CSHCS office or the Family Phone Line for information.

Q. What if I want to go to different doctors than the one my private insurance says I have to use?

A. You must follow all the rules of your insurance. If you don't CSHCS can not pay either.

Frequently Asked Questions

Q. When medical care is needed for a condition that has nothing to do with the eligible diagnosis, what do I do?

A. If you think the condition may qualify for CSHCS, contact your local CSHCS office. If the condition is not? CSHCS covered condition we cannot cover it. Depending on your income, you may qualify for Medicaid or MIChild, which could also help.

Q. Should I tell my provider about my Medicaid coverage?

A. Yes. Medicaid pays for services such as medical care not related to the eligible diagnosis.

Q. If I have any other health insurance, should I tell the provider?

A. Yes. Providers must bill other insurance before CSHCS. You will need to show your insurance card or give the provider these details:

- Policy & Group Numbers
- Name of Employer
- Social security number of policyholder

Q. What if I want to go to different doctors than the one my private insurance says I have to use?

A. You must follow all the rules of your insurance. If you don’t CSHCS cannot pay either

Q. What should I do if I receive a bill from a provider for a service I thought CSHCS would cover?

A. **DO NOT IGNORE THE BILL.** If the provider is a doctor, hospital, or ambulance and is not listed on the Eligibility Notice, call your local CSHCS office to see if the provider can be authorized. If the provider is already listed or does not have to be listed, contact the provider and ask him or her to bill CSHCS.

Q. Can we be reimbursed by CSHCS for bills we have already paid?

A. No, you cannot. Sometimes the provider is willing to bill us and pay you back. Check with your provider.

Q. What should I do if there are any changes in the family household or medical care?

A. Contact your local CSHCS office and report any changes to name, address, family size, income, phone number; insurance coverage, insurance card and provider changes.

Frequently Asked Questions

Q. How do I get equipment or medical supplies?

A. **Make sure an approved CSHCS medical specialist writes the prescription. Check with your medical supplier.** Some services require CSHCS approval ***before*** you get the service. **If you have other insurance, you must get prior approval from that carrier and CSHCS.**

Q. What if out-of-state care is recommended?

A. Out-of-state care always requires special approval. To process your request, we need the written recommendation of one of your CSHCS approved Michigan medical specialist and the name and address of the out-of-state provider. Your local health department may be able to help find a provider in Michigan.

Q. What should I do when the CSHCS coverage year is about to end?

A. About three months before coverage ends, contact your local CSHCS office to see if a medical review or a financial update is needed to renew coverage. CSHCS will also send you a notice of what is needed.

CSHCS reviews medical eligibility. Depending on the primary eligible diagnosis, you may not need to have medical eligibility determined every year. We require updated financial information every year.

Q. What should I do if I believe I need more help in meeting the eligible person's needs?

A. Call your local CSHCS office. You may be eligible for additional services. There may be community resources available to help you.

Q. What if I don't agree with a CSHCS decision about services?

A. You have the right to appeal the decision and ask for a Departmental Review of any decision. For details of the process, call your local CSHCS office.

Q. What if I need help with transportation costs while my child is in a hospital away from home?

A. Check with your local CSHCS office to see if you qualify for transportation assistance. We also may be able to help with transportation costs for medical appointments.

Q. What if I want to talk with another family who has medical needs similar to ours?

A. Call the Family Phone Line at 1-800-359-3722. Our statewide Family Support Network of Michigan is made up of support parents who are trained to listen to your concerns and to share information about resources.

Frequently Asked Questions

Q. What if I have a question that isn't answered here?

A. Ask any questions about the CSHCS Program or covered services by calling your local CSHCS office or the CSHCS Family Phone Line: 1-800-359-3722.

Definitions

Acute: A condition that happens suddenly and lasts a short time. It is the opposite of "chronic."

Care Coordinator: A CSHCS care coordinator helps to link clients and their families with community services and resources. The care coordinator works with the client and family, primary care provider, medical specialist, school, therapist and other services providers in an organized fashion in order to help the client achieve maximum good health.

Children's Special Health Care Services (CSHCS): A program within the Michigan Department of Community Health which helps children and some adults with special health care needs, and their families. One way that it helps is by covering costs of specialty care associated with their CSHCS covered condition.

Children with Special Needs Fund: A special fund available to families of children with special needs to help pay for special equipment or services that are not covered by CSHCS or any other public health care program. The fund also helps where the person is eligible for CSHCS but not enrolled.

Chronic: An illness or condition that slowly persists or progresses over a long time. It is the opposite of "acute."

Chronicity of Condition: CSHCS considers a condition to be chronic when it requires specialty medical care for a year or more.

COBRA: After job loss, a worker's health care coverage may continue under the Consolidated Omnibus Budget Reconciliation Act (COBRA). Read details under "Health Plans and Benefits"at the U.S. Department of Labor's website: www.dol.gov

CSHCS Medical Consultant: A licensed pediatric specialist who reviews CSHCS cases, determines medical eligibility, and considers special requests.

Diagnosis: The name of a condition or illness. To qualify for CSHCS, an individual must have a CSHCS covered diagnosis where activity is or may become so restricted by disease or deformity as to reduce normal capacity for education and self-support. CSHCS can cover more than one diagnosis per person.

Diagnostic Evaluation: The process of identifying a disease or condition from its signs and symptoms; a careful examination of facts to try to understand or explain the cause of an illness.

Disability: The result of any physical or mental condition that affects a person's ability to develop, achieve, or function.

Definitions

Early On (Part C of IDEA): A program for Michigan infants and toddlers through age 36 months who have special needs and their families. The Michigan Department of Education coordinates it. However, early intervention services it provides come from many different agencies, programs, and professionals in each community. For details call 1-800-Early On (1-800-327-5966).

Eligible: Meets specific requirements to qualify for a program or services.

Eligibility Notice: A letter CSHCS mails to families approved for CSHCS enrollment. It gives dates of CSHCS coverage and may list the providers approved to provide care or services.

Enroll: To go through the process by which CSHCS signs up an individual to get medical care and treatment for an eligible diagnosis.

Evaluation: A way of collecting information about an individual's needs, strengths, and interest.

Family Phone Line: The Family Center of CSHCS operates a toll-free Family Phone Line (1-800-359-9722). Staff helps answer questions, solve problems, and give information about CSHCS and health resources.

Family Support Network of Michigan (FSN): A statewide network of parents of children with all kinds of special needs, regardless of CSHCS enrollment. Services include peer support and information.

Health Care Professionals: Workers who have special health care skills. They include nurses, doctors, social workers, physical therapists, pharmacists and so on.

Health Maintenance Organization (HMO): A medical insurance program which gives care through specified doctors and hospitals.

IDEA: Individuals with Disabilities Education Act. A federal law authorizing special education for children.

Income Review/Payment Agreement: A CSHCS form the family uses to report the annual income and that states the annual amount a family agrees to pay for CSHCS coverage.

Definitions

Local Health Department: The local county office where one or more CSHCS representatives are located. This office can also provide free or low-cost basic medical care and other health-related services.

Medicaid: Federal and state health care coverage for low-income or medically needy individuals and working families that qualify.

Migrant Worker: Individuals, who work or seek work in agriculture or a related seasonal industry and moves away from their usual home to a temporary residence as a condition of employment.

Need for Treatment by a Physician Subspecialist: The condition must require the services of medical and/or surgical subspecialists at least annually, as opposed to being managed exclusively by primary care physicians.

Occupational Therapy: Treatment to help a person develop mental or physical skills to aid in daily living. It focuses on hand and finger movement and self-help skills, such as dressing or using a fork and spoon.

Pediatric: The branch of medicine dealing with the care of children.

Pediatric Specialist: A physician specialist who has a specialty area of knowledge, skills, and training, to treat children.

Pediatrician: A doctor who specializes in caring for children.

Physical Therapy: The treatment of disease by physical and mechanical means, such as massage, regulated exercise, water, light, heat, and electricity.

Primary Care: General or basic health care. Traditionally provided by a pediatrician, internist, or family practitioner.

Definitions

Primary Payer: The company or organization that must be billed first for CSHCS-covered services before CSHCS will consider payment. By law, CSHCS is always the last to pay.

Prior Approval: The CSHCS process which gives a provider approval to provide certain services or equipment, as needed before it is supplied.

Provider: A person, organization, or company that provides medical care, medications, medical supplies, or equipment.

Respite: A temporary period of rest or relief for caregivers that provide daily care to an individual enrolled in CSHCS.

Severity of condition: The rating by a MDCH medical consultant of the need for specialty medical care. The decision is whether care would prevent, delay, or significantly reduce the risk of activity becoming so restricted by disease or deformity as to reduce the individual's normal capacity for education and self-support.

Specialist: A medical practitioner whose practice is limited to a particular type of patients (such as children) or of diseases (such as skin diseases) or of technique (such as surgery). Typically, a specialist is qualified by advanced training and certification.

Sub-specialist: A physician who has a *subspecialty*, meaning a narrower field of specialization. For example, pediatric cardiology is a *subspecialty* of general cardiology.

Support Parent: A parent of a child with special needs who gives one-to-one support to other parents.

WIC (Women, Infants and Children): A program that provides supplemental nutrition, breastfeeding information, and other resources to foster healthy mothers and babies.

Sources :MEDLINEplus, a service of the U.S. National Library of Medicine and the National Institutes of Health, and CSHCS

Looking Ahead

What is Medical Transition?

Medical Transition is the time when teens move from pediatric services to adult services. This may mean seeing new health care providers. It also may mean using adult health care coverage.

Often, transition into adult services is stressful for families. Your son or daughter may worry about making health decisions. You may worry about losing input into complex medical care. Or, you may need to take legal steps to make decisions for your adult child. In either case, medical transition can be challenging.

CSHCS issues when your teen turns 18

- Young adults can give CSHCS permission to communicate with a person(s) they trust by filling out and sending an Authorization to Disclose Protected Health Information form.
- The Income Review/Payment Agreement must include only your son or daughter’s income.
- Your son or daughter must sign the CSHCS application, unless you are legal guardian.
- If capable, your teen needs to carry his or her mihealth card and CSHCS Eligibility Notice to every appointment.
- If capable, your teen needs to begin working with the CSHCS representative in your local health department. An example is calling to add providers.

What families can do to prepare

- Plan early. The move to adult care may not happen until age 18, 21, or even older. It is still important to plan ahead. Planning for special educational transition begins around age 14. That is also a good time to start planning medical transition.
- Find out about adult providers in your area. Research adult services. Research your child’s options for health care plans. Find out when it is time to make the transition into adult care. Pediatric providers and CSHCS representatives can help.
- Talk to your child’s pediatric providers. Get referrals for adult providers. Find out what adult services they may be eligible for at age 18. Your local health department can help with referrals and information on services.
- Choose whether you or your child will manage his or her care or if you will share responsibility.

Looking Ahead

Youth as managers of their own health care

For teens to become independent adults they need family members to take less active roles in their medical care. In this way they gain independence and skills.

To plan for and assist in medical transition, families can:

- Provide your child the opportunity to meet with health care providers in private. Let them ask questions about their health. This will allow your son/daughter to gain important skills in managing their own care.
- Encourage your child to learn about their medical condition(s). They should know what they are going to the physicians for. They should know basic information about their condition. If taking medications, they should know the names of medications. Also, why they take them.

How teens can prepare

This is an important time in your life. Here are tips on medical transition:

- Learn about your health care needs.
- During appointments with your physicians, spend some time alone with them. Ask questions about your health. Or, ask anything else you want to know.
- Be involved. Try to plan your next doctor's visit. Make sure that physicians and other adults talk directly to you. Don't be afraid to ask questions about your care!

Parents as managers of an adult child's health care

Many youth with special health care needs may need assistance with care into adulthood. Below are tips on what parents and family members may do to prepare for medical transition.

- Include your son or daughter in their care as much as possible.

- Have medical information readily accessible to your family and to providers. That guarantees information is on hand even when you are not near.

Looking Ahead

Guardianship and Alternatives

At age 18, a teen becomes his or her own guardian. Some youth are unable to handle that due to severe cognition or physical disability. If so, you may face tough legal choices. Questions to ask yourself are:

> "What are my main concerns for my child's future? Are they financial, medical, or emotional concerns?"
>
> "What decisions will my child be able to make on his/her own?"
>
> "What decisions will my child need assistance making?"

Think about what you would like to secure for your child's future. Below is a list of choices a family may consider. The list does not include all options. Other choices may be best for your family.

- **Full Guardianship** provides full decision making rights to an appointed guardian.
- **Partial Guardianship** provides rights in certain areas of decision making to an appointed guardian.
- **Durable Power of Attorney** allows health care decisions by an appointed guardian. Power of Attorney can cover other decisions.
- **A Patient Advocate** acts for the individual receiving care. Most hospitals and providers have information on this choice. The appointed individual might be a family member or friend.
- In a **Conservatorship** an appointed individual manages a person's finances.
- A **Representative Payee** manages the finances of a person with SSI or SSDI benefits. Applications and help are available at local Social Security Administration offices.

Many of these actions must be done through the court system. Start exploring them at least by the time your child turns 17. There may be legal and court fees for each. Seek qualified legal counsel.

For more resources, contact local human service agencies or the local health department.

The Next Pages are for You To Write Important Information About Your Child

All About My Child

Child's Information

Name: First ____________________ Middle ____________ Last ___________________

AKA ____
(Also Known As) (If child uses two different last names, please include)

Nickname: ____

Address ______________________ City ___________ State _______ Zip Code ________

Phone: (_____) ____

Date of Birth: Month ________ Date _________ Year ________ Blood type: _____

Diagnosis: ____

Special Care Instructions: ____

Current Medication(s)	Dosage and Administration
____________________	____________
____________________	____________
____________________	____________
____________________	____________
____________________	____________
____________________	____________

Allergies: ____

Child's Preferred Language: ____

Child's Ethnicity: ______________________ Religion :____________________
(race)

Parent(s)/Primary Caregiver(s) _______________________________________

Address ____________________City ____________State ______Zip Code ________

Family's Preferred Language: ____

Phone: *Mother* Home (____) ___________ Work (____)___________ Cell (____)___________

Father Home (____) _________ _ Work (____) ___________ Cell (____) ___________

Primary Home (____) ___________ Work (____) _________ __ Cell (____) ___________
Caregiver

Family's religion and/or customs that may
affect the medical treatment or health care of ______________________________
(child's name)

____

____

____

____

Special Dietary Needs (Kosher, Vegetarian, etc.):

What to AVOID!

(food, dust, animals, etc.)

Emergency Contact Person/s:

Name

Address City State Zip Code

Phone ( ) Relationship

Name

Address City State Zip Code

Phone ( ) Relationship

Others Who Should Be Present/Called (Clergy, other relatives and friends)

Name ______________________________

Address ______________________ City __________ State ________ Zip Code __________

Phone (_____) ______________________ Relationship ______________________

Name ______________________________

Address ______________________ City __________ State ________ Zip Code __________

Phone (_____) ______________________ Relationship ______________________

Child's Preferences

Child's preferred language: ______________________________

Way of Communicating: ______________________________

(American Sign Language; use of special equipment: TTY, communication board, etc.)

Specific words/gestures with special meanings: ______________________________

____

____

Likes: ______________________________

____

Dislikes: ______________________________

____

____

Child's Strengths ______________________________

____

____

Favorites

Food(s):

____

____

Songs:

____

____

Music:

____

____

Toys:

Friends(s):

Other People/Things:

Anything else you would like to tell providers:

Building Health Partnerships

Building Health Partnerships

Adapted from

Tips from and for Parents: Building Early Intervention Partnerships With Your Child's Doctor

Washington State Department of Social and Health Services

www1.dshs.wa.gov/iteip/Publications.html

There are many steps you can take to create the type of partnership and relationship that you want with your child's doctor*. Below are ideas for starting or improving a partnership.

- For ease, the word "doctor" is used. These ideas also apply for nurse practitioners, physician's assistants, and other health providers.

Choosing a Doctor

Here are general qualities to seek:

Clinical skills and knowledge

Does he or she have the training and specialty interests important to your child's needs? A doctor with a special interest in child development, special needs, or a specific, diagnosis might be just right.

Experience

Has the doctor cared for other children who have a similar diagnosis as your child or for children with developmental delays or disabilities in general? That kind of experience can help your doctor to be more aware of resources and services that might benefit your child and family.

Mutual respect and sense of connection

Is he or she approachable? Does she or he make you feel comfortable? Do you like the interactions with your child? Do you trust the person with the health of your child? A doctor may be better in one area than another.

Choosing a doctor may mean choosing a balance between technical skills, interpersonal skills, and experience.

It's up to you to decide what you and your child need right now. You may find that what you need changes over time.

Building Health Partnerships

Creating a Relationship

Be a partner

Decide what type of partnership you want with your child's doctor. How do you want him or her to be involved in coordinating care and services for your child? What role do you want in making medical and health decisions?

Whatever type of partnership you have, you should feel comfortable asking questions, sharing your insights, and feel like you and the doctor are part of a team.

In turn, you should be open to the doctor's questions and insights and accept him or her as part of your child's team.

Be a role model

Show by example how you want to be treated and how you want your child to be treated.

If you want the doctor to listen to you, then be a good listener, too. If you want your doctor to be delighted with your child, then show your delight in your child.

Be understanding

Doctors often must have appointments back-to-back, every 15 minutes or even sooner. If it seems that the doctor is in a hurry to move on to the next appointment, you are probably right!

If you need more time, let her know and she should be willing to work this out.

Let the doctor get to know your whole child. Talk about the good things as well as your concerns. Share pictures and stories so he or she can appreciate and get to know your child.

Express gratitude

Say thank you, in person or in writing. Let your doctor know what is helpful and when he or she is doing a good job.

Don't expect perfection

Every relationship has bumpy times and so will this one. Be willing to make changes, if needed. Recognize that doctors are human, too, and give him or her the chance to make things better.

If you are mostly pleased with your child's doctor, then it may be worth working through rough times.

Building Health Partnerships

Practicing Good Communication

A two-way conversation

Think of communicating with your doctor as having a friendly, respectful conversation. That means it is two-way and both of you should share your questions, concerns, successes, and hopes.

Get clear about how to communicate

Ask your doctor how to best communicate about your child's care. Is there a good time during the day to call? Does she or he prefer that you first talk to the office nurse if you have questions between appointments?

Are there ever situations when the doctor would want you to call him or her at home? Does your doctor welcome communication via email? How about fax?

Feel okay about needing advice between appointments

If you have a concern between appointments and feel that you need or want an answer from your child's doctor, ask the nurse to have him or her call you.

Explain that you are more worried than usual – for reasons you may not be able to explain just yet – and that you would really appreciate talking directly to him or her.

Reflecting

Were you able to discuss your most important questions or issues? If not, is this okay with you or is there a plan for how you will get the information you need? Did you feel like a partner in your child's health care team? Is there something you might want to do differently next time?

Building Health Partnerships

Deciding to Change Doctors

Parents are often pleased with their child's doctor. But sometimes things just don't feel right. Here are questions to ask yourself:

- Does the way the office is run work for you?
- Is the doctor available when you need him or her?
- Are you often confused about recommendations and why certain treatments are prescribed?
- Do you feel like your concerns are not taken seriously?
- Does this make you question and doubt your instincts or your doctor's?

Trust your gut. If the relationship doesn't feel right and you haven't been able to make it better, then know that it is time to change doctors. Try to do it in a positive way.

"Thanks for all you've done for my child. We really appreciate the time you have spent with us. But right now this is not the perfect fit for our family – I would like my child to see someone else."

Building Health Partnerships

Getting the Most Out of an Appointment

Scheduling

To cut down on waiting time, schedule the doctor's visit for the first appointment of the day or right after lunch.

If you have questions or concerns that may take more time than usual, ask the office staff to schedule a longer appointment. Your doctor and staff will appreciate the advance notice and you will feel less frustrated about not having enough time.

Preparing

Think about what you would like to get out of the appointment ahead of time:

Gather reports that you especially want to discuss. For children getting *Early On* services, be a link between the doctor and the program. Share questions and concerns back and forth.

Make a list of your questions, concerns and other information you would like to share. It is okay to bring up things that don't seem related to health but still matter to you and your child. Decide what on your list is the most important to you.

Ask the doctor if he or she would like a copy of your questions and concerns ahead of time. Emailing, faxing or dropping your list off before the appointment might give more time for the doctor to prepare more complete responses to your questions.

Participating

Share your list of questions and concerns at the start of the appointment. The doctor likely has his own list for what he needs to accomplish during the visit. Together you might need to decide what to discuss during this appointment and what to discuss later.

Building Health Partnerships

Things can move so quickly during appointments that it can be hard to remember all that is said. Here are some ideas to help with remembering:

- Take notes. Use the same notebook to write down your questions and the answers at each appointment. This will make it easier to keep track of all the information over time.
- Bring someone along who can help listen and take notes – and be there to support you, if needed.
- Sometimes you might need to get the conversation back to your concerns. Here are ways to do that:
- Ask questions: What do you suggest about…?
- Tell a story about something going on in your child's life that you want to discuss.
- Simply change the topic: *"One other thing I would like to talk to you about is…"*

If your doctor gives you information that is upsetting or hard to understand, ask if you can call later to go over your questions.

Updating

Tell your doctor about your child's progress. Ask questions and share any concerns.

A fun and memorable way to update a doctor is to send an occasional picture of your child with a note highlighting his or her progress.

"Here is my daughter having fun at dinnertime. Through Early On, I learned how to encourage her to eat more table foods. She doesn't gag and cry at the sight of food anymore and I'm not so worried about her growth. Early intervention helped me have a better relationship with my daughter and helped my family, too – mealtimes are no longer a battle. Thanks for the referral!"

Community Resources for Children with Special Health Care Needs and Their Families

These organizations offer either INFORMATION or DIRECT SUPPORT in the areas indicated. When trying to link to the web addresses below, please place the mouse directly over the web address.	Child Care for Children with Special Need	Paying for Health Care Services	School and Learning	Support Groups orOthers Like Me	Understanding the Problem or Condition	Help with Problem Solving	Fun and Recreation
Children's Trust Fund (child development, parenting resources, child abuse prevention) 800-CHILDREN (244-5373) www.michigan.gov/dhs				x	x	x	
Community Coordinated Child Care 866-424-4532 www.mi4c.org	x					x	
Developmental Disabilities Institute 888--978-4334 www.wayne.edu/ddi		x		x			
Diabetes Diagnosis and Treatment of Children at Clinics Across Michigan Wayne State University Morris J. Hood Jr. Comprehensive Diabetes Center 888-324-6852		x			x	x	
Domestic Violence Hotline 1-800-799-SAFE www.ndvh.org				x	x	x	
Down Syndrome Society 800-221-4602 www.ndss.org	x	x	x	x	x	x	x
Early On Michigan 800-372-5966 www.earlyonmichigan.org	x	x	x	x	x	x	x
Easter Seals of Michigan 800-292-2729 www.essmichigan.org		x	x	x	x	x	x
Epilepsy Foundation of Michigan 800-377-6226 www.epilepsyfoundation.org/michigan	x	x	x	x	x	x	x
Exceptional Parent Magazine 877-372-7368 www.eparent.com			x	x	x	x	x
Family Center for Children and Youth with Special Health Care Needs (Children's Special Health Care Services/ Michigan Dept. of Community Health) 800-359-3722				x	x	x	x
Family Support Network of Michigan 800-359-3722				x	x	x	

Community Resources for Children with Special Health Care Needs and Their Families

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Genetics Support Group Directory (for families affected by known or suspected genetic diseases, birth defects, and related conditions) http://www.michigan.gov/mdch/0,1607,7-132-2942_4911_4916-170467--,00.html				X	X		
Head Start in Michigan 866-320-6472 www.mhsa.ws		X	X	X	X	X	X
Hearing Program 800-359-3722 TTY 517-335-8246 www.michigan.gov/ehdi	X	X	X	X	X	X	X
Hemophilia Foundation of Michigan 800-482-3041 www.hfmich.org	X		X	X	X	X	
Hope Network 800--6957273 www.hopenetwork.org	X	X	X	X	X	X	
Immunizations 888-76-SHOTS (88-767-4687) www.michigan.gov/mdch		X			X	X	
Juevenile Diabetes Research Foundation 800-533-2873 www.jdrf.org		X		X	X		
Kids as Self Advocates (KASA) 785-273-3398 http://www.fvkasa.org/				X		X	X
Latino Family Services 313-841-7380 http://www.lsa.umich.edu/psych/di/partners/latinofamily.asp				X		X	
Lead Poisoning Information 800-MI-TOXIC (648-6942) www.michigan.gov/leadsafe		X					
Learning Disabilities Association of MI 888-597-7809 www.earlyonmichigan.org/ld/home.htm							
Merck Patient Assistance Program (for pharmaceuticals) 800-727-5400 www.merck.com		X					

These organizations offer either INFORMATION or DIRECT SUPPORT in the areas indicated. When trying to link to the web addresses below, please place the mouse directly over the web address.	Child Care for Children with Special Need	Paying for Health Care Services	School and Learning	Support Groups orOthers Like Me	Understanding the Problem or Condition	Help with Problem Solving	Fun and Recreation
Michigan Donated Dental Services 866-263-4067 http://nfdh.org/joomla_nfdh/content/view/68/105/		X					
Michigan - Official Site 517-373-1837 www.michigan.gov	X	X	X	X		X	X
Michigan's Assistive Technology Resource (MATR) 800-274-7426 www.cenmi.org/matr			X		X	X	
Michigan Association for the Education of Young Children (MiAEYC) 800-336-6424 www.miaeyc.com		X					
Michigan's Children 800-330-8674 www.michiganschildren.org						X	
Michigan Dental Association Find A Dentist/Community Programs 517-372-9070 www.smilemichigan.org		X				X	
Michigan Department of Human Services 517-373-2035 www.michigan.gov/dhs							
Michigan Head Start Association 517-374-6472 www.mhsa.ws		X	X	X		X	
Michigan Insurance Bureau 877-999-6442 www.michigan.gov/ofis		X				X	
Michigan Medicaid Program 888-367-6557 http://www.michigan.gov/documents/MedicaidCoveragebrochure_15697_7.pdf		X					
Michigan Protection and Advocacy Services 800-288-5923 www.mpas.org		X	X	X	X	X	
Michigan Office of Special Education and Early Intervention Services http://www.michigan.gov/mde/0,1607,7-140-6530_6598---,00.html			X	X			
Michigan Parents of Children with Visual Impairments 989-855-2430 800-292-7851 x601 www.napvi.org			X	X	X	X	X

Community Resources for Children with Special Health Care Needs and Their Families

These organizations offer either INFORMATION or DIRECT SUPPORT in the areas indicated. When trying to link to the web addresses below, please place the mouse directly over the web address.	Child Care for Children with Special Need	Paying for Health Care Services	School and Learning	Support Groups orOthers Like Me	Understanding the Problem or Condition	Help with Problem Solving	Fun and Recreation
Michigan Vulnerable Adult Helpline 800-996-6228 www.michigan.gov/dhs				X	X	X	
MIChild Health Insurance (for uninsured children of Michigan's working families) 888-988-6300 TTY 888-263-5897 www.michigan.gov/mdch		X					
Migrant Head Start 800-782-7831 http://www.michaglabor.org/telamon/CenterList2006.htm		X	X	X		X	
Mothers United for Moral Support (MUMS): National Parent to Parent Network 877-336-5333 (parents only please) www.netnet.net/mums					X	X	X
National Dissemination Center for Children with Disabilities 800-695-0286 www.nichcy.org		X	X	X	X	X	X
National Institute on Deafness & Other Communication Disorders 800-241-1044 TTY 800-241-1055 www.nidcd.nih.org					X		
National Organization for Rare Disorders (NORD) 800-999-6673 www.rarediseases.org				X	X		
Parenting Awareness Month & Prevention Network (substance abuse) 800-968-4968 • www.preventionnetwork.org					X	X	
Parent Empowerment Project 800-262-0650			X		X		X
Parent HELPline 800-942-4357 • www.michigan.gov/dhs							X

Community Resources for Children with Special Health Care Needs and Their Families

These organizations offer either INFORMATION or DIRECT SUPPORT in the areas indicated. When trying to link to the web addresses below, please place the mouse directly over the web address.	Child Care for Children with Special Need	Paying for Health Care Services	School and Learning	Support Groups orOthers Like Me	Understanding the Problem or Condition	Help with Problem Solving	Fun and Recreation
Runaway and Homeless Youth Program (RAP line) 800-292-4517 • www.michigan.gov/dhs		X		X	X	X	
Social Security Administration 800-772-1213 www.ssa.gov			X	X			
Special Olympics Michigan 800-644-6404 www.somi.org							X
Spina Bifida Association of America lists Michigan chapters 800-621-3141 www.sbaa.org		X		X	X		
Saint Francis Camp on the Lake 517-688-9212 http://www.saintfranciscamp.org/							X
Starfish Family Services 24-Hour Crisis: 313-563-5005 734-728-3400 www.starfishonline.org			X	X	X		
Stepfamily Association of America 800-735-0329 www.saafamilies.org				X	X	X	
Together Let's Cope (TLC) Support Group for Parents of Premature Infants St. John Hospital Neonatal Intensive Care Unit 313-343-3683 www.stjohn.org				X	X		
Very Special Arts of Michigan 313-832-3303 www.vsami.org							X
Wild Swan Theatre 734-995-0530 www.wildswan.ws							X
Will Rogers Institute (pulmonary disease/ disorder education and research) www.wrinstitute.org					X