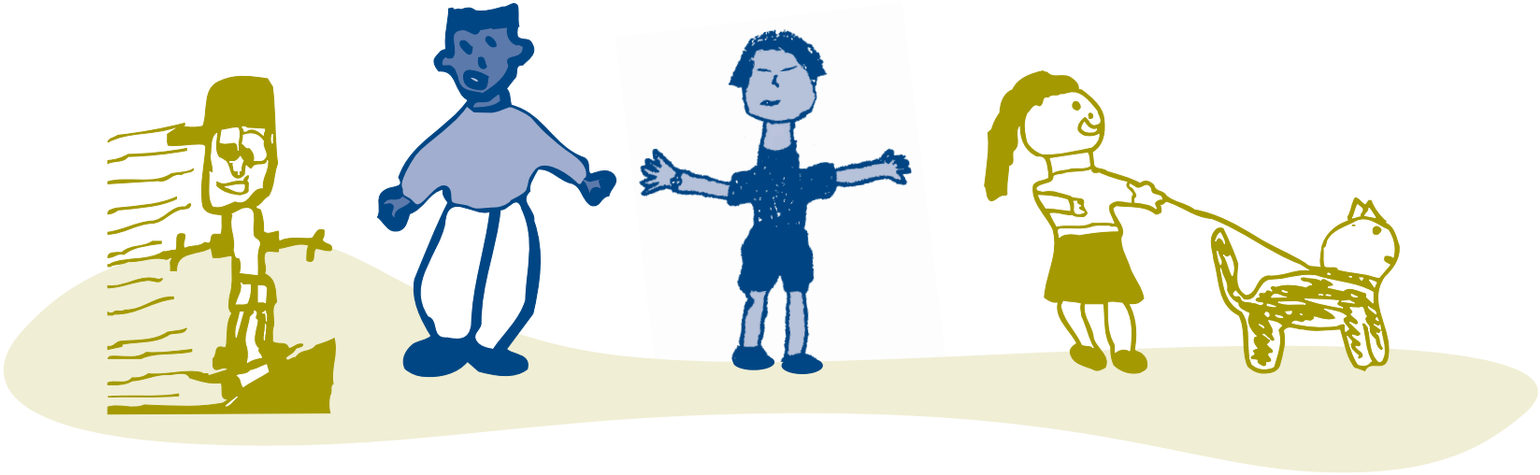
Finding Your Way In Managed Care

A Guide for Washington Families of Children with Special Health Care Needs



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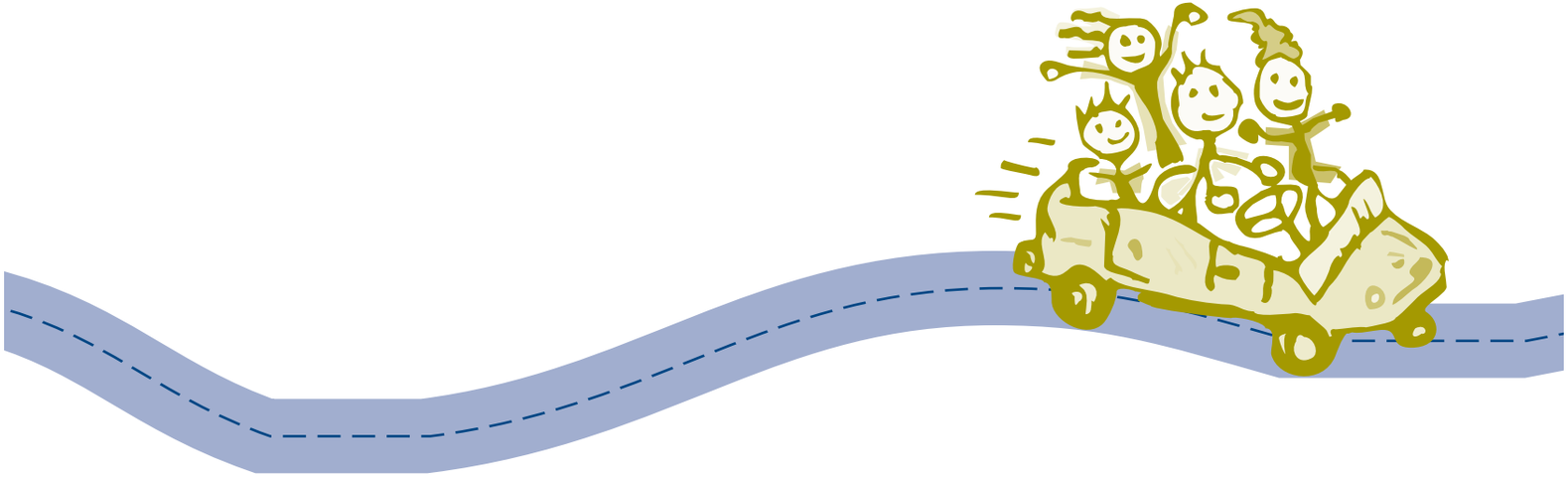

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1 Navigating the Managed Care System

The way that you get health care, how it is paid for, and the guidelines or rules you need to follow are changing. "Managed care" is becoming one of the most common systems for providing health care, but many families are still trying to learn what it is and how to use it.

Navigate: To make your way. To plan, record, and control your course and position as you travel.

Many people talk about "navigating the managed care system." When you navigate the system, you are travelling through it. In a way, you can think of a journey that will take you and your child to the services and treatments your child needs. Your journey may have direct routes, or twist and turn through challenging detours. It may take many phone calls, doctor visits, therapies and decisions before you get where you want to go.

Who are "children with special health care needs?"

Children with special health care needs are children who have a long-term physical or mental health condition or a developmental disability. Children may need services from medical specialists as well as their primary care doctor. Specialists may include therapists who help improve your child's skills in many areas, including movement, speech, and behavior.

This guidebook will help you understand some of the routes you may take as you look for a managed care plan or provider and make choices about the health care services your child needs.

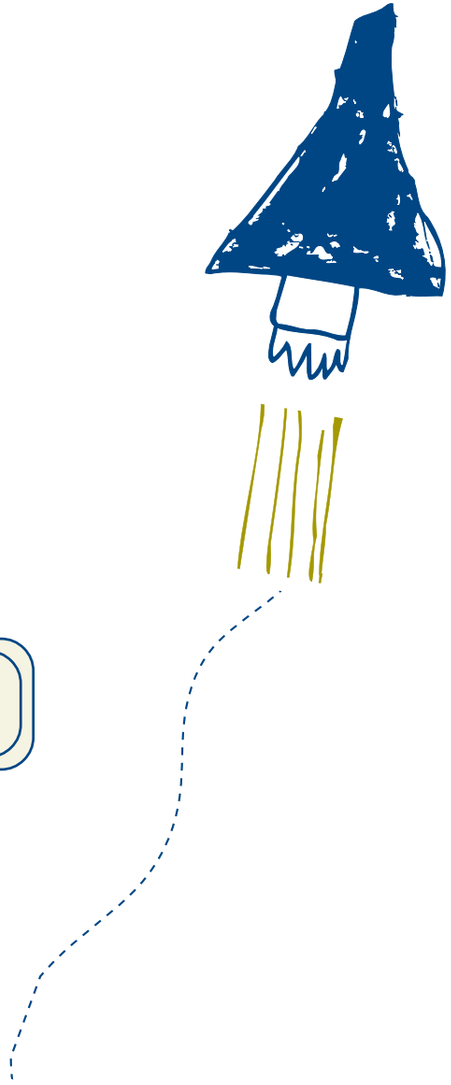
Tips for making the most of this guidebook

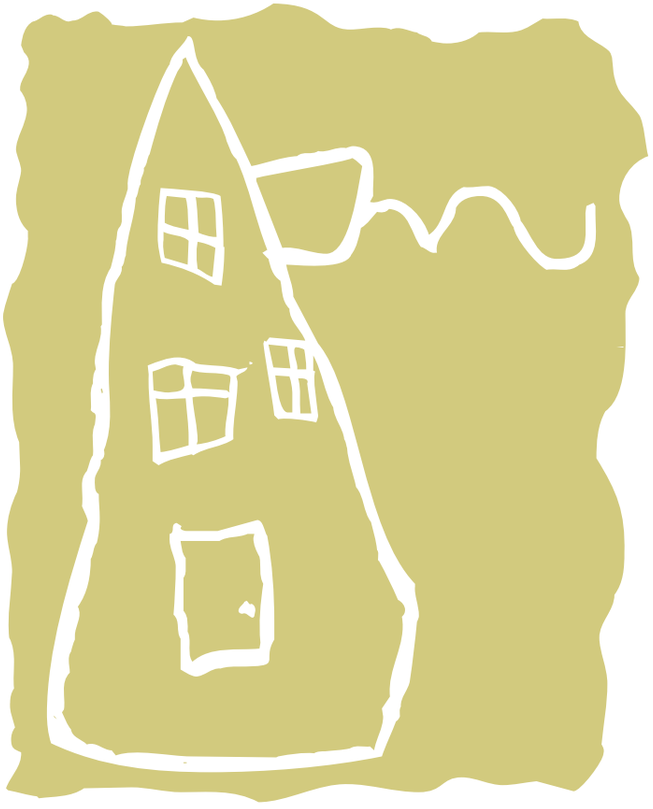
- Look for road signs along the way. They will give you the meanings of important terms, remind you of what's ahead, or warn you about possible dangers.
- Health and insurance terms may seem like a foreign language or alphabet soup! When you find a word or phrase that you don't understand, look in the Glossary of Useful Managed Care Words beginning on page 61 to find the meaning. Just after the Glossary you will find a list of acronyms. An acronym is a shortened version of a group of words. For example, a primary care provider is sometimes called a PCP.
- Keep asking questions until you get the information you need. Learn as much as you can about your health care benefits and the plan you are in. Stay focused on your goals and your child's health.
- Getting the right mix of health care services for your child with special needs can be confusing and difficult. When the road gets bumpy or you feel like you've reached a dead end, don't give up! There are many resources. Ask for help from your health care providers. Find other parents who can give you tips. Go to the member services department of your managed care organization and ask questions, or look for other avenues to get the services your child needs.

This guidebook will help you understand managed care and get the services your child needs.

It will help you

- Learn how to choose a plan and primary care provider SEE CHECKLISTS ON PAGES 22 & 25
- Learn terms you'll need to talk with your child's primary care provider SEE GLOSSARY ON PAGE 61
- Know what questions to ask and how to ask them SEE CHECKLIST ON PAGE 21
- Find out about your child's health benefits SEE PAGE 17
- Know what to do if the answer is "No" SEE PAGE 38
- Locate other resources SEE PAGE 49





2 Building a "Medical Home" for Your Child

What is a medical home?

Every child deserves a medical home, especially when the child has a health condition or a developmental disability. A medical home is an idea about how to provide health care and community services in a coordinated way. It's not a place. It's a relationship with a group of doctors, nurses and other health care providers who know you and your child.

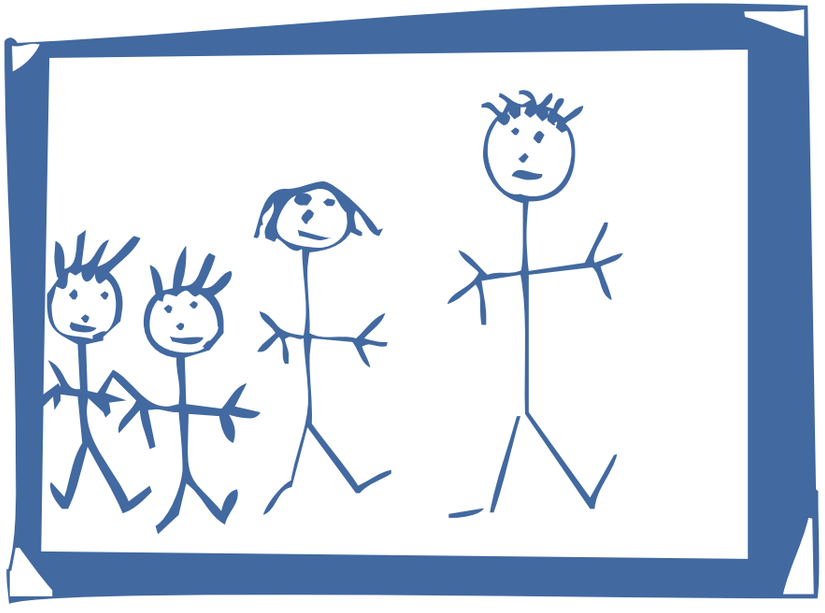
In managed care, your medical home is usually with your primary care provider. The primary care provider might be a medical doctor, physician's assistant, nurse practitioner or another health provider. Sometimes a specialist is a primary care provider (PCP).

In a medical home, your PCP

- Knows and respects your child and your family
- Understands your child's and family's needs
- Provides routine care like regular checkups and shots (immunizations)
- Works as an equal partner with you to make decisions about your child's health and services
- Coordinates your child's care and helps you understand your choices and recommendations from others

To make managed care work for your child with special health needs, you need to see yourself as an equal partner on the team that makes decisions about your child. You, your child's doctor, other health professionals and the managed care organization make up the team.

As a parent, you know your child best. Your knowledge is important to the team. Learn to share your thoughts and concerns. Listen carefully and ask questions to get a clear understanding. Remember that everyone on your team is working toward a healthy future for your child!



3 Getting to Know Your Child's Primary Care Provider (PCP)

Names for the primary care provider (PCP)

- M.D., Medical Doctor
- D.O., Osteopathic Doctor
- Pediatrician, Internist, Family Practitioner
- A.R.N.P., Advanced Registered Nurse Practitioner
- N.P., Nurse Practitioner
- P.A., Physician's Assistant

Your child's primary care provider (PCP) is the doctor, physician's assistant, nurse practitioner or other health provider who sees your child first, whenever medical care is needed. In managed care, the primary care provider holds the key that opens the gate to specialists and other services. An honest and trusting relationship with your child's primary care provider will help you figure out what kinds of services your child needs. Good communication will help the PCP to learn more about your child and your family. Sometimes parents are the teachers. Mutual learning is part of being in a medical home.

In addition to being the key person who refers your child to specialty services, your child's PCP is also the person who provides regular checkups and preventive care for your child. These services are important to your child's health.

Tips for building a good relationship with your child's primary care provider

- Find a primary care provider within the managed care plan who understands your child's issues, respects you and your family, and will work with you to address your child's needs.
- Keep in touch with your child's primary care provider. Go in for scheduled visits and follow recommendations for checkups and preventive care.
- Share the good news as well as the bad news to give a complete picture of who your child is. You may want to send a school photo or an occasional note of thanks to let your PCP know that you appreciate his or her help and good work.
- Write down your questions and concerns, so you have a list ready when you call or see your doctor.
- Ask for help from your primary care provider. If you don't understand something, ask for more information. If you still have questions, ask for written information or another appointment. Take a friend or family member to the appointment with you.
- Find another person in the doctor's office who can help you with questions, referrals and services if the doctor isn't available. A care coordinator, nurse, case manager or other staff member may be able to assist you.
- Keep written records about your child. Have a notebook to write down appointments, medical treatments, therapy, prescriptions, personal needs, allergies, preferences and even telephone conversations. It will help you and your child's providers remember what was said or done in the past. Take it with you when you visit your doctor.

LOOK ON PAGE 53 TO FIND OUT ABOUT A CARE NOTEBOOK FOR YOUR RECORDS

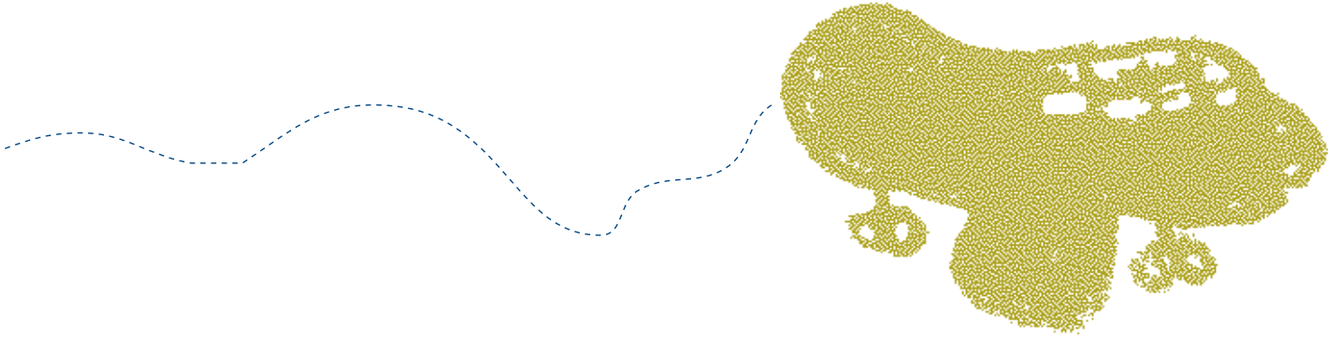
4 Understanding the Basics of Managed Care

Managed care is not new. What is new is how much managed care is used in Washington. Every managed care plan is a little different, but all managed care plans have some things in common. It is important to understand the basics of managed care in order to use it well. If you are used to getting your health care services the "old fashioned" way, called fee-for-service, managed care can seem frustrating.

What makes managed care different?

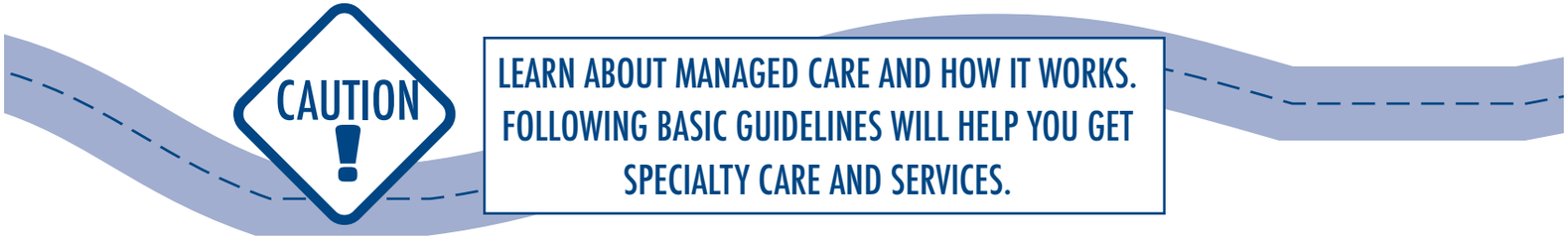
Managed care is different than fee-for-service coverage. Fee-for-service involves paying for each doctor visit, lab test, day in the hospital, and so on, as separate items on a bill.

In managed care, services are paid for in advance through monthly premiums and co-payments. This can make getting health services a lot easier since there are usually not as many forms to fill out or bills to pay. No matter how many times your child goes to the doctor, sees a specialist, or goes to the hospital, the managed care plan covers the expenses, as long as the monthly payments are made and the service is a covered service. (Note: it is important to go through the proper steps, which include seeing the primary care provider first, to make sure you get an approval for services. Otherwise, services may not be paid by the plan.)



Here are some of the ways managed care differs from fee-for-service

- In managed care, you belong to a health plan and are called a “member” of the plan. Most medical care is offered through one source: your plan and its network of providers. In fee-for- service you don’t “belong” to a plan and you select your own providers.
- A primary care provider (PCP) must usually see your child first. Recommendations or referrals for specialty services will then be made based on what is seen and talked about at the visit.
- Each managed care plan works with specific providers and specialists, called a “network” or “panel” of providers. Your choices may be limited to only those named by your plan.
- The primary care provider may talk with other providers about your child’s needs, in order to get more coordinated care for your child.
- Payments and billings are handled differently. There are no deductibles or bills to be submitted for payment or reimbursement. Costs are paid in advance through a monthly premium (which may be paid by you, your employer or the state). You may pay only a small co-payment at the time of each visit or for each prescription.
- There is a focus on preventive care. Regular checkups and preventive care are covered benefits. By seeing your PCP regularly you may be able to avoid high-cost emergency room and hospital visits.



LEARN ABOUT MANAGED CARE AND HOW IT WORKS. FOLLOWING BASIC GUIDELINES WILL HELP YOU GET SPECIALTY CARE AND SERVICES.

If your child has special health needs, it is especially important to learn how to find your way in managed care. You must understand the step-by-step process that will allow you to move through the system and get the services your child needs.

Managed care is based on preventive care and the goal of avoiding expensive medical crises. This approach helps people stay healthy, since problems can be caught earlier. Preventive care includes regular checkups and well child visits.

Managed care's focus on prevention can work well for children. It helps everyone keep an eye on children's growth and development, problems can be caught early, and children can get special treatments and services early in their life.

Referrals

Specialty care can be critical for some children with special health care needs and is an important part of the managed care system. Remember that specialty care, including therapy, must be approved before you go for the visit. The first step is to get the referral from your PCP or your health plan or both. If your child goes to a specialist without prior approval, you may have to pay the charges yourself (without reimbursement from your health plan).

Referral: **Approval for services from a specialist, therapist or hospital that includes an agreement to pay costs for the visit.**

A referral usually covers a specific service for a certain time. It may be for only one appointment or for a certain number of visits. Ask for a written copy of the approved referral request. Keep copies in case a question comes up about payment.

Before starting your journey through managed care, remember that all managed care plans are not the same! Some may be better than others in meeting your child's special health care needs. It is important to find a plan that works for you and your child.

Some ways managed care plans differ

- Locations of services
- List of doctors, hospitals, pharmacies and other services you can use (called the "panel" or "network of providers")
- Ways of doing business. There are many different types of managed care. Some of the more common ones are:
  - Health Maintenance Organizations (HMO)
  - Preferred Provider Organizations (PPO)
  - Point of Service Plans (POS)

SEE THE GLOSSARY OF USEFUL MANAGED CARE WORDS ON PAGE 61 TO GET A SHORT DESCRIPTION OF EACH ONE.

Benefits Information

As you look at health care benefits, you will find that they differ a great deal. Some benefits packages may look alike in writing but actually work very differently because of the way services are delivered!

Benefits are set by the managed care organization (MCO) and the purchaser of your health coverage. The type of coverage and costs are described in a contract between the MCO (or insurance company) and the purchaser. The purchaser may be your employer, the state, the federal government or yourself.

You will be in a better position to get what you want if you understand your benefits package. Benefits for each plan should be described in a member handbook. Take time to read about the benefits offered. It may be confusing! Talk to your benefits manager at work or a representative of the managed care plan to help you sort through your coverage.

Don't limit yourself to asking only your employer or representatives of the plan about how the plan works! A great way to get information about a plan is to ask families who use the plan how it works for them. Think about what your child needs. To get started read the ***Making Choices*** section of this book beginning on page 21.

Some managed care organizations may offer two or more different benefit packages (remember, it depends on what is negotiated with the purchaser). So, even if a friend has the same health plan, don't assume that your benefit package is the same as your friend's. Check out the details for yourself.

It is important to remember that your health care benefits may change whenever your situation changes. For instance, benefits may change if you do any of the following things

- Change employers
- Switch between Medicaid or other state paid coverage and employer-paid health insurance
- Purchase your own individual policy instead of having an employer-paid group policy (individual policies usually cost more and cover less)!
- Move from one part of the state to another. Some plans do not offer statewide coverage.

Here are some questions to ask that will help you understand how benefits are provided

- How many providers specialize in the care of children? (Providers who specialize in the care of children are called pediatric providers.)
- Who are the providers that specialize in treating children with the medical condition my child has?
- Are there special clinics that focus on certain kinds of health conditions, especially the condition my child has?
- What kinds of family support programs are offered to members of the plan? Family support programs are services like a resource room, library or Internet web site, or classes that teach parents about child development, parenting, respite care and how to care for a child with special needs.
- Are case managers or care coordinators available to help arrange services? How can I find out about them?
- Are there interpreter services, transportation services or after hours and weekend clinics?
- How are complaints and appeals handled?

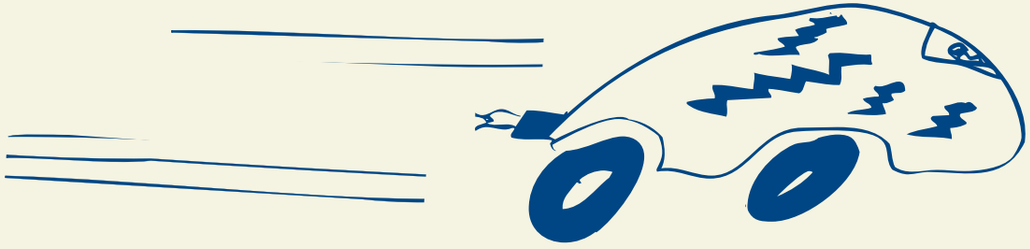
Tips on benefits

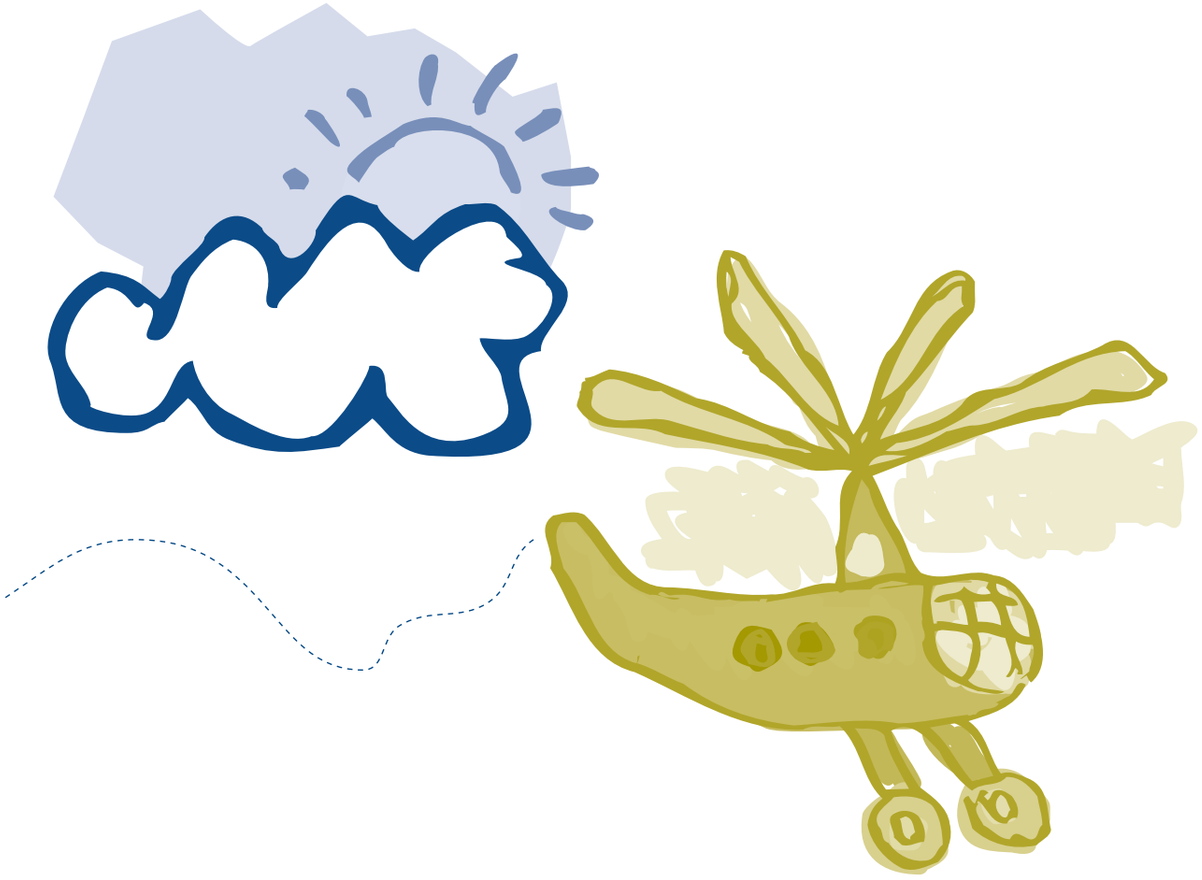
For Healthy Options families

If you are a Healthy Options member, all of the plans offered to you have similar benefits. But, there are still differences in the plans, especially in how benefits are provided and which providers can be used. Some may work better for your family than others. Check carefully before enrolling in a plan. Use the checklists in this guidebook to help you make a decision.

For families with commercial managed care

Commercial benefits packages (those offered by employers) can be very different from one another. Employers arrange coverage based on what they can afford and what they think their workers want. Both the benefits and how those benefits are delivered will vary from plan to plan. Sometimes you do not have a choice in plans, because your employer offers only one. Still, it is important to know what is offered and how services are delivered, so that you can get the best use of your coverage.





5 Making Choices

Choosing a managed care plan

Think about your child's health care needs now and in the future. It may help if you make a list and talk about each item with your family members, a health care provider or a close friend. Then write down what is most important.

Here are some questions to consider

- ? Does my child have delays in growth or development, or a long-term (chronic) medical condition?
- ? What kind of health services and therapies does my child need now? What else might be needed next year?
- ? Which of the providers that care for my child now are most important to us?
- ? Does my child need special equipment or supplies?
- ? Does my child need medicines?
- ? What are the needs of others in our family?

By answering these questions you will learn what is most important to you when deciding on a plan. Other questions may come up as you are thinking about your needs. Write them down, too. Your answers will help you look at and find which managed care plan has the benefits, services, or providers that fit your child's and your family's needs.

Which health plan is best?

If your child needs a particular service, or you want a particular provider, begin your selection process with that in mind. Many families choose their managed care plan because they like a certain doctor, clinic or hospital. Find out which managed care network (or MCO) has the providers or services that are most important to you. If you have a favorite provider ask which plan he or she belongs to. Many providers belong to more than one managed care network.

Here are some questions to help you begin the process of finding a plan that works for you. Make copies of the checklist and record your answers for each plan you are considering.

Checklist for choosing a health plan

Provider Network and Specialists

- ❑ Can I get a current list of the providers who are part of this plan?
- ❑ Which providers, including specialists and therapists, specialize in working with children?
- ❑ Can we still see the specialists my child uses now?
- ❑ Are hospitals and clinics that specialize in the care of children included in the plan? Where are the hospitals and clinics located?
- ❑ Are there doctors in the plan who specialize in my child's diagnosis or disability?

Equipment and Supplies

- ❑ What coverage is offered for equipment and medical supplies? Are there limits to coverage?
- ❑ Where can I get equipment and supplies? Am I required to use only certain companies for equipment and supplies?

- Who has to approve my requests for equipment and supplies?
- Will the plan pay if my child's equipment must be rented or purchased?
- Will the plan pay when my child's equipment must be repaired?
- How often can equipment be replaced as my child grows?

Pharmacy Coverage

- Are prescription medicines covered? Am I responsible for any of the cost?
- Do I have to get them from certain places?
- Are there limits on which medicines are covered? Are there policies about the use of generic (no-name) drugs rather than brand name drugs? Are the medicines we use on the list of drugs (called a formulary) that the plan will pay for?

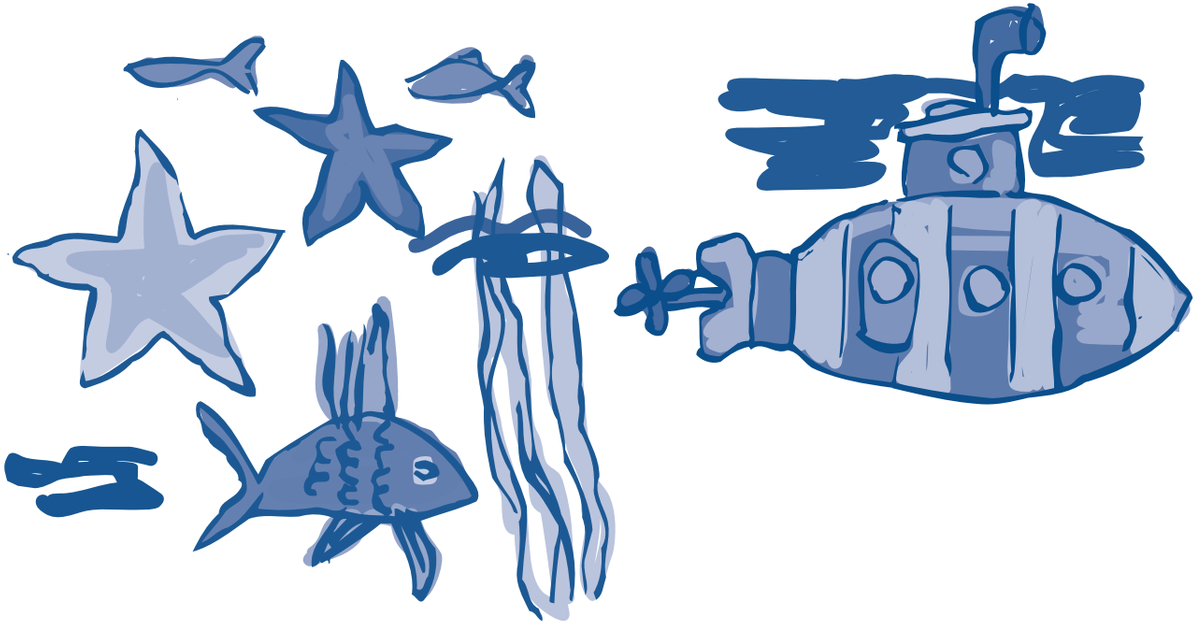
Other services

- Does the plan cover mental health services, counseling, dental care or vision care? What are the limitations?
- Are there classes, informational materials, and family support groups for my child's diagnosis/disability?
- Will the plan pay for transportation?
- Is there home health care available through the plan? Are there specific agencies or providers that we will need to use? Are there limits to how much home care is covered or how often we can use it?

- ❑ If I don't speak English, are translation services available at the clinics and by phone?
- ❑ If I have a hearing impairment, is there a TDD or TTY?
- ❑ Can we get someone to help us coordinate our child's care and services?

Complaints, Appeals, and Grievances

- ❑ Will the plan pay if I want a second opinion from a different doctor?
- ❑ What are the rules about filing a complaint or appealing a decision I don't agree with?
- ❑ If I have a complaint or disagreement, is there someone in the plan who will help me? (This might be a patient advocate.)



Choosing a Primary Care Provider

IF YOU ALREADY HAVE A TERRIFIC PCP WHO YOU REALLY LIKE AND TRUST, FIND OUT WHICH PLANS HE OR SHE IS IN. YOU MIGHT WANT TO JOIN THAT MANAGED CARE PLAN.

Which primary care provider is best for my child?

Choosing a primary care provider (PCP) is an important step in your journey. The PCP is a key person who will provide health care to your child, work to arrange and coordinate services, plan for your child's future needs, and help you get the information, services and referrals you want.

Try to find someone you can talk with, someone who will listen and respect you and your child. Many different health care providers can serve as a PCP (refer back to page 11, ***Getting to Know Your Child's PCP***). Depending on where you live and the providers in your plan, your choices will vary.

If you need to select a new primary care provider

- Ask other parents if they know anyone who is an expert in your child's diagnosis or if they have a PCP they particularly like. Find out why.
- Talk with other professionals you know or who have worked with your child. Ask who they recommend. For example, your child's early intervention therapist may be helpful in finding a good PCP for your child.
- Make an appointment to get to know the provider before you decide. Both you and your child will depend on your PCP, so you want to find someone you like and can trust. Be sure to ask if the health plan will charge you for this type of visit.
- Consider how important it is to find a provider who specializes in the care of children, who understands growth and development issues, and who will make referrals.
- In some communities, choices of plans and providers are limited so it may take extra work to find a provider or get the referrals to specialists that you need.

Sometimes even the best primary care providers do not know what kinds of community resources are available to children with special health care needs. Try to find out who has this kind of information. You may want to start in the "Resources" section of this book. Share any information you have or find with your provider. Tell your member services department that resource information is very important to you.

To select a PCP, consider asking some of the following questions. Think about what is important to you and your child. Then try to think of more questions you might want to have a provider answer and write those down.

Checklist for choosing a primary care provider

- ❑ Do you belong to any of the health care plans that I can choose from? Which ones?
- ❑ Do you plan to stay with them?
- ❑ Who is in your network? Which specialists can you refer my child to?
- ❑ If my child has to go to the hospital, which hospital would you send him or her to? Is it a children's hospital?
- ❑ What does it take to get a referral to a specialist? Is a referral good for a specified length of time, or is a referral needed for each visit?
- ❑ Who makes the decisions about referrals? How long does it take?
- ❑ Are you in a sub-network? Who is in your sub-network?

SUB-NETWORKS ARE DEFINED ON PAGE 66

Provider's Qualifications

- ❑ Have you cared for other children with my child's diagnosis? How many? How long ago?
- ❑ What is your background? What credentials and licensing do you have?
- ❑ Do you have any specialized training?
- ❑ Are you available after normal working hours? How can we reach you?
- ❑ When you are not available, who will take your place? What are their credentials? What experience do they have with my child's diagnosis?
- ❑ Do you make house calls?
- ❑ How will you handle my child's needs? (Describe your child's symptoms and behavior.)
- ❑ Will other members of your staff have specified roles in the care of my child, like case management or care coordination?
- ❑ How long will you keep seeing my child? Will you see my child after he or she turns 18 years old? If not, how will you help us find and work with another provider?
- ❑ When I call with a problem or question, how long will it take you to get back to me? Are there certain times during the day when you return phone calls?
- ❑ Do you send out reminder notices for regular checkups and shots (immunizations)?

Care coordination and links with community services

- How will you help provide and coordinate services for my child?
- How do you work with and communicate with people in the schools or community who provide services to my child? Will you help us with our individualized education plans (IEPs)?
- What kinds of family support services are available through your office? Where are they offered? If we need other services or supports that you don't offer, will you or your staff help us find it?

Plans Change, Services Change

Remember: After you've done all your homework and found a good primary care provider and specialists for your child, things can and do change!

A provider may leave the plan. (If your PCP leaves the plan, you will probably receive written notice through the mail.)

The benefits contract may change. In fact, every year most employers make new agreements about health care coverage. The new agreements may affect your benefits.

When the contract changes or the provider leaves the plan, you'll probably want to look at the situation again to be sure your child's needs are still covered. Ask yourself whether you need to look for a new PCP or make other changes.

Time out for questions!

What do I do if our child sees more than one provider, and some of the providers are not in our new plan or network?

You will need to figure out which provider or providers are the most important to you and your child. Don't forget to ask if there is a sub-network of providers. You may have to give up some of your current providers and look for new providers. Ask other parents which primary care providers and specialists they see. Follow up any recommendations with a phone call or visit, if possible. Use the checklists in this guidebook to help you ask questions.

We have a favorite provider, and he is not with our current plan. Can we switch to a different plan?

Talk with your employer, the benefits office at your job. or Healthy Options to see if you can switch plans. Explain why you want to change and the important role your provider has in caring for your child.

Each plan has an open enrollment period when you can switch plans. For many plans, this happens only once a year. Find out when your plan offers "open enrollment." If you are in Healthy Options, you can change plans more often than once a year.

If you cannot switch plans at this time, ask whether there is another provider in your current plan who is qualified to provide your child's care.

CAUTION !

Beware of switching plans or providers too often. You may lose "continuity of care." Continuity of care is the result of a medical home: providers know you and your child, they know what has happened in the past, what your needs and goals are, and what may be expected in the future. When you change providers, you may need to take time to educate them about your child and build a new relationship.

What are the good things about your current plan? If you find that you cannot switch plans (perhaps the plan is not offered by your employer), you may need to find a new provider.

? What do I do if our provider leaves our plan?

Ask your plan representatives if you can get a referral to the same provider for several months or longer, until you can find a new provider.

Refer to the checklists in this guidebook to help you find a new provider. If you can't find a qualified replacement, you have at least two options:

- Ask for an ongoing referral. Be sure to emphasize the impact a change might have on your child's health and the continuity of care.
- Find out if you can change plans in order to keep your relationship with your provider. (Ask the benefits department at your work or Healthy Options whether you can switch plans.)

? We want to go outside our plan to see a specialist who isn't in our network of providers. Can we?

It may be possible to see a specialist outside of your plan. However, be sure you understand what is involved and whether there are any additional costs. If you want the plan to pay for the costs, be sure to get written approval first. Plans may approve outside services if there are no specialists of the type you need within the plan or network. They may give approval in some very complex cases, too.

Sometimes you may need to request an “exception to policy” from your health plan in order to see an outside specialist. Work with your doctor or other health providers to submit the paperwork needed to get an exception to policy.

In most managed care plans, you must get approval before going to the outside provider! Otherwise, you may be responsible for paying the costs yourself. Be careful before you sign any forms that may make you financially responsible for the cost of care. Sometimes these forms are called waivers. If someone asks you to sign a waiver, stop and make sure you understand what your options are!

If you have Healthy Options coverage, only sign if you are willing to pay. There may be other ways to get the care and services you need without being charged. By signing a waiver, you may be taking on large debts.

? What is a co-payment? Do I need to pay at the time of service?

In managed care, a fee is usually charged each time you go to a provider, get a prescription filled, or purchase equipment and supplies. This fee is called a co-payment (or a “co-pay”). Show your member card each time you receive medical services, including prescriptions and specialty services. It will tell what co-payment you may be required to pay.

At this time, families in Healthy Options do not have to pay co-payments.

Do I need to get medicines, medical equipment or supplies from specific locations in order for the plan to pay for them?

Yes! Managed care plans make agreements with doctors, nurse practitioners, therapists, home health agencies, pharmacies and people who sell medical equipment (called equipment vendors) to their members. Learn who you can go to and be careful to use only the service providers in your managed care plan.

If you get prescriptions, supplies, services or equipment from those who do not have agreements with your health plan, you may have to pay the charges yourself. This is called going "outside the plan" and can be very expensive!

What are networks of providers?

Networks and sub-networks are groups of providers that may include doctors, nurse practitioners, specialists, pharmacies, equipment vendors, other providers and even hospitals. Each network or sub-network may have guidelines about services, referrals and how payments are made.

Networks and sub-networks may limit your choice of providers. Find out how this might affect your child. Talk to your child's doctor and figure out which specialists are in his or her network and sub-network.

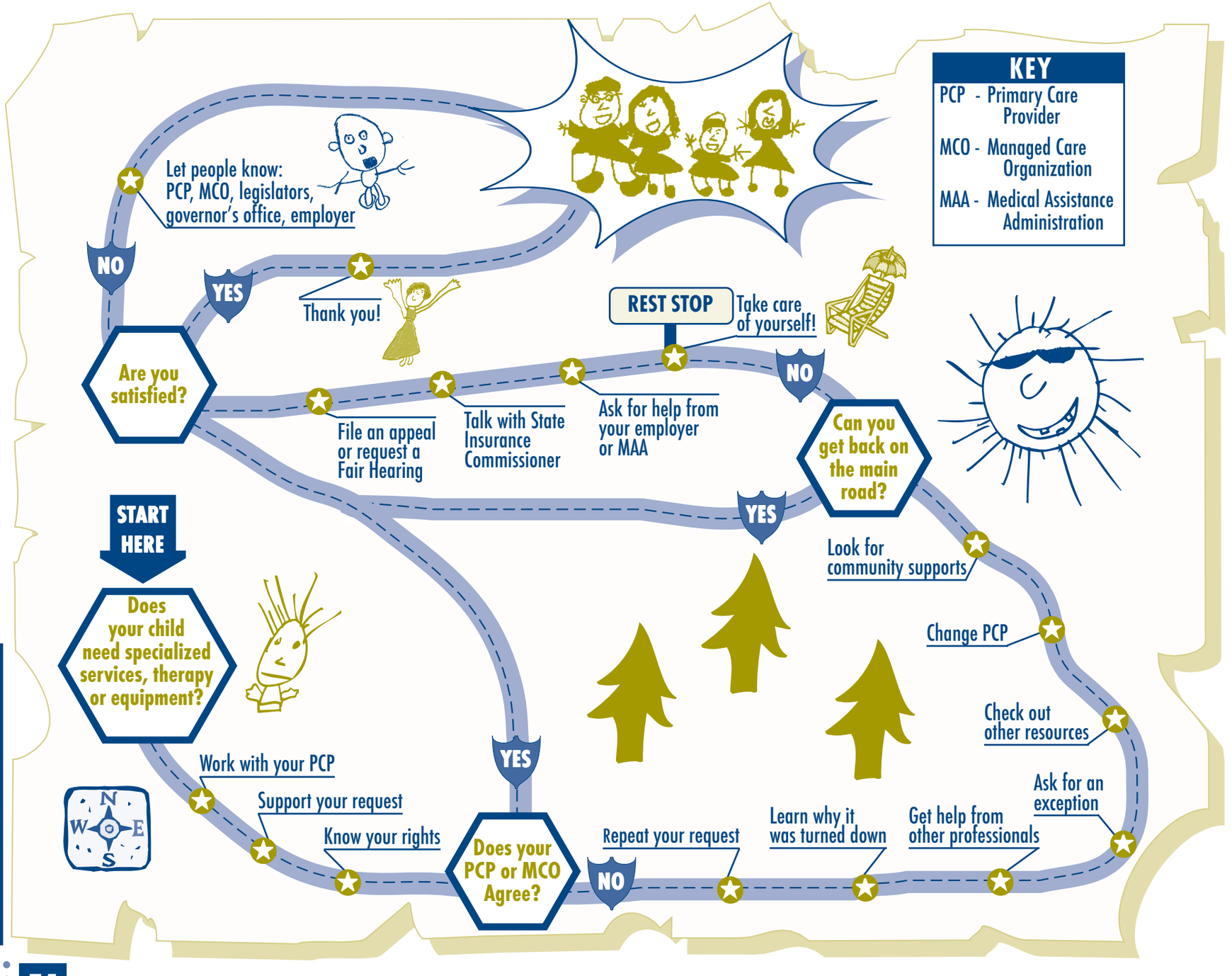
. . . . Time to move on

6 Finding Your Way: A Managed Care Map

Once you've chosen a health care plan and a primary care provider, your journey to find services and therapy begins. As your child grows and changes, many decisions will have to be made. The map that follows will help you understand the choices you have along the way.

How to use the map

This map shows some of the routes you may take as you work your way through the managed care system. The options shown on the map may help you choose which actions to take. Some of the routes focus on moving forward when you get a "YES" answer to your requests, are happy with your health care and are getting the services you need. If you are not satisfied with your health care or are denied services, the other routes will give you options to consider.


KEY
PCP - Primary Care Provider
MCO - Managed Care Organization
MAA - Medical Assistance Administration
START HERE
Does your child need specialized services, therapy or equipment?
Work with your PCP
Support your request
Know your rights
Does your PCP or MCO Agree?
YES
NO
Repeat your request
Learn why it was turned down
Get help from other professionals
Ask for an exception
Check out other resources
Change PCP
Look for community supports
Can you get back on the main road?
YES
NO
REST STOP
Take care of yourself!
Ask for help from your employer or MAA
Talk with State Insurance Commissioner
File an appeal or request a Fair Hearing
Are you satisfied?
YES
NO
Thank you!
Let people know: PCP, MCO, legislators, governor's office, employer
N
W
E
S

Does your child need the services of specialists?

Your child may have very clear medical needs, like asthma, diabetes or chronic illness. Other special health needs may be harder to see at first, like difficulty learning to walk or talk.

A provider may be the one to point this out to you during a routine visit, or you may sense that something is wrong. Parents can sometimes tell that something is "not quite right" with their child, even though they have not received a diagnosis or taken their child to the doctor. If you feel worried about your child's health or development, talk about your concerns with your child's primary care provider.

Usually a PCP is trained to care for common childhood conditions and illnesses and to watch growth and development. Providers who have additional training in certain disorders or more complex conditions are called specialists.

You may want your child to be treated by a specialist if

- Your primary care provider recommends it
- Your child's condition persists without expected improvement
- Your concerns are not being addressed and you feel your child would benefit from specialized care

Get the services your child needs

When your child needs to see a specialist, the primary care provider will help you begin the process of getting a referral. (A referral is the pre-approval needed in order for specialty services to be paid by the managed care plan.) Plans may differ in the way they go about approving a request for specialty care. Find out what is required in your plan and how long the whole process takes.

In some plans, referrals sent by your PCP will be reviewed or approved by a review committee, administrative manager, or other people who are not health care professionals. Sometimes, it takes more than one try to get a referral approved.

Here are some things to do that may help you with the referral process

- Work with your child's primary care provider to ask the MCO to approve your request for specialty services. Clearly explain why you think it is necessary.
- Talk regularly with your PCP and repeat your concerns.
- Keep written, organized records on your child's care and progress. Collect articles about your child's condition and other information to support your request. Ask other professionals to submit letters of support for your request.
- Talk with other families who have had concerns like yours and learn about strategies they have used.
- If the managed care organization does not approve a service or referral request, it can refuse to pay. Read on to learn about what to do if the answer is NO!

REMEMBER: THE FIRST DENIAL DOES NOT HAVE TO BE THE FINAL ANSWER.

BE PERSISTENT! SAY IT ONCE, SAY IT TWICE, AND IF YOU DON'T GET ACTION, SAY IT AGAIN.

Know your rights!

As you navigate the managed care system, you need to know your rights and the rights of your child. Some of your legal rights are provided by state law.

- You have a right to file a grievance or appeal if you disagree about the provider's or plan's decision.
- You have the right to a second opinion. A state law, Washington Administrative Code (WAC) 388-538-120, protects this right.
- You have the right to get continued services while you are appealing a decision. State law, WAC 388-538-110, guarantees you this protection.
- If you are in a Healthy Options plan, you can request a Fair Hearing if you have a problem that doesn't get resolved. A Fair Hearing is another form of appeal that is intended to give an unbiased answer when a request has been denied. Each Community Services Office (CSO) of the Department of Social and Health Services (DSHS) has a Fair Hearing Coordinator. Call the CSO or Healthy Options to get the number. You can also write to the Office of Appeals, Department of Social and Health Services, P.O. Box 2465, Olympia, WA 98507-2465.

To find out more about your rights

- Look in your member handbook
- Call the Office of Insurance Commissioner: 1 (800) 562-6900
- Consult an attorney or legal aid

What to do if the answer is no!

If you ask for services and the answer is no, or if you get an answer that you don't agree with, first try working with your child's PCP and the managed care plan to reach a decision that meets your needs.

Here are some options:

- Discuss your concerns with your PCP. Bring in letters of support from other professionals, articles or your own records that show unmet needs or reasons the services are important for your child.

- Call the customer service/member service telephone number for your managed care plan and ask for the reason or reasons that your request is not covered by your health benefits. Be sure to write down the name of the person you spoke with, and briefly what was said. If your questions weren't answered, find out who will follow up with an answer for you and when you can expect to hear from them.

- Ask to have your request reconsidered. Often a second request is approved if it stresses how important the service is to you and your child and how it will meet health needs. It is especially helpful to point out how your request may reduce or prevent future health care costs.

- Be sure that you understand the reason the answer was no. Sometimes a reason is given that is confusing, like "not medically necessary" or "not a covered benefit." Ask for written information in plain language to make it clear to you. It's okay to ask more than once and to ask for answers to be written in a way that you understand.

- Sometimes, you may need services that are not included in the policies of your managed care plan. In that case, if you believe that a request is essential to your child's health, you may want to ask for an exception to policy. Find out who can approve an exception to policy and how long it will take. Be sure to think carefully about your request and clearly state why the services are important. An exception to policy may require a lot of work and not many are approved.

- If you think your request is more likely to be approved by a different primary care provider you may want to consider changing your PCP. But remember to do your homework and consider how changing providers might affect your child's continuity of care.

If you have tried these suggestions without success, you may wish to file a formal appeal or go through the steps to file a complaint. Sometimes a complaint is also called a grievance. Each plan has written policies and steps to follow for filing appeals and grievances. Call your plan's customer service number or check in your member handbook to find out exactly what you need to do. Follow the guidelines carefully and be sure that you meet the time frames and deadlines that are required.

Don't give up!

Some plans have policies that require third party review and/or arbitration. This means that someone outside the plan reviews an appeal or complaint to be sure that it was fairly considered. If you have Healthy Options coverage and you do not agree with a decision, you can request a Fair Hearing.

You might want to look for help with your request from sources outside of the managed care plan. Possible sources include the Washington State Insurance Commission, advocacy groups, your legislators, or the governor's office.

The Washington State Insurance Commissioner's Office is a useful source of information and assistance. Many families call the Insurance Commissioner's Office long before they have problems, because there is a great deal of useful information and counseling available from the staff.

If you can't get what you need through your health plan, look for resources in your community that will pay for services or therapies. Contact local groups like Kiwanis or Lions Clubs or other charitable foundations. Check to see if the service is available at a Shriners Hospital for Children; Shriners services are provided at no cost for most children. Call the public health department in your area, and ask for a nurse who has experience with children with special needs to help you find more choices.

At some point, you may want to think about changing health plans if you think you can get better services somewhere else. (But don't leave one plan until you are sure that you have the coverage you need with a new plan!)

Take care of yourself

Remember that this is not an easy job. It takes time and hard work. You need to take care of yourself! Your family will reap the benefits.

- Don't be surprised if you feel discouraged sometimes.
- Find support from other families. Get involved in a parent to parent group. (See list of resources in the back of this guidebook.) Other parents of children with health needs like your child's are great sources of information and support. Connecting with them may lighten your load.
- Find time to rest. Ask someone else to do part of the work.
- Find time to play. Keep up with your favorite hobby, sport, or other recreational activity, even if it is only for a few hours a week.
- Seek help for child care/respite.
- Listen to your own feelings and act on them. You really do know your child best and if you think that something is not right, it probably isn't.
- Think and talk about how you see your child's future, all that you want for his or her life, not just medical care and treatments.

7 Helpful Hints and Sample Letter

Sample Phone Calls

Below are some examples of how you might talk with plan representatives if you need information or disagree with a decision.

If You Need a Second Opinion

1. *Call your Health Plan's customer service number, and explain the situation.*

   Parent: "Hello, my name is Susan Jones and I am calling about my son, John Jones. His chart (or member) number is 111-22-333. My son is a year old and I am worried about his growth and development. I talked to our doctor, Dr. Smith, at the First Street Clinic. He wants to wait and see but I don't want to wait any longer to find out what is happening."

2. *Tell the plan representative that you disagree. Ask for a second opinion.*

   Parent: "I don't agree with this decision and am very concerned about my son. I want to see another doctor who specializes in the care of children. Under Washington law, I am entitled to a second opinion."

3. *Ask what the plan will do to help resolve the issue.*

   Parent: "Does this plan have other doctors who specialize in this area? What other options are available to me?"

   Plan Representative: "I will send you a list of pediatricians in your area who can give you a second opinion. The list will include phone numbers for the clinics."

4. *Be sure to find out how long it will take to get information or services.*

Parent: "I need to schedule an appointment soon. When can I expect the information?"

Plan Representative: "I will mail the list today. You should receive it by Friday. If you haven't received it, please call me. My name is Mary Harris and my direct line is 555-0000."

5. *Be courteous and let them know you are writing down information about the call.*

Parent: "Thank you for your help. I have written down your name and phone number to call if I don't receive the information."

If You Disagree with a Decision

1. *Give your name, your child's name and chart number as in the sample above. Then tell why you are calling.*

Parent: "I received a letter from ABC Health Plan that said my request for physical therapy for my daughter was not approved. It did not explain why the request was denied or how I can appeal the decision. I have reviewed my policy and do not find a reason that the request sent by our doctor was denied."

2. *Clearly say what you want to happen:*

Parent: "Please tell me in words that I can understand, why the request was declined and how I can appeal this decision."

Plan Representative: "I will have to look up your benefits and find out why your request was not approved. I will send you the rules you need to follow to appeal this decision."

3. *Ask how long it will take them to get information or answers to you.*

Parent: "When can I expect your call? It is important that we continue therapy. I will appeal this decision. I know that Washington law protects our rights to continue services during an appeal."

Plan representative: "It will take some time to study your file. I will call you back within seven business days. I will also mail you a booklet that tells you how to file an appeal. You should receive it in three days."

4. *Be sure to write down what was said, the name of the person you spoke with and what you talked about.*

Parent: "I have noted your name and phone number in my records. I prefer to have you send a letter telling me why our request was not approved. I will expect the letter and a copy of your appeals guidelines within seven business days so that I can begin the appeal. Thank you for your help."

Helpful Hints for Writing a Letter of Appeal

1. It is better to address your letter to a specific person instead of a general department or the managed care plan itself. Try to find out who will be making the decision and send the letter directly to that person.
2. Be sure to show your child's name and chart or account number within the plan, your address, and phone number.
3. Begin your letter with a brief statement of who you are and why you are writing.
4. If you are requesting a written explanation of the reason for denial, state that you have reviewed your contract and can't find a valid reason for the denial in your policy. Ask for specifics, not just a response that states "not a covered benefit" or "not medically necessary."
5. If you are appealing a denial, state your understanding of the denial and explain why you feel the services are necessary and/or should not be denied. Use any articles, research, or other supporting professional opinions.
6. Include dates and names of people in the managed care plan you have already talked with.
7. Ask for a response (a letter, meeting or phone call) within a reasonable time. State a date that you want to hear back from the plan. Don't wait too long. Your plan may have very limited time periods to file an appeal.
8. Have someone proofread your letters.
9. Keep a copy for your personal records.
10. Send copies to other important people who have helped you.

Here's a Sample Letter!

October 25, 20XX

1 Dr. Jane Doe
Medical Director
ABC Health Plan
1000 Main Street
Seattle, WA

Dear Dr. Doe:

2 Re: John Jones Chart No. 111-22-333

I am writing this letter to file an appeal for the denial of coverage for physical therapy for my son John Jones. At this stage of his development the ongoing physical therapy is critical and will prevent the need for costly surgery in the future. 3

On September 20, 20XX I received a letter denying payment for the August, 20XX visits for the reason it was not a covered benefit. I read my handbook and discussed the denial with our pediatrician, Dr. Ed Moss. We agreed to resubmit the request with more information about my son's condition, the benefits of physical therapy and the risks of stopping the therapy. On October 5, 20XX I received a second letter saying that the visits were not covered. 4 6

5 I spoke to Mary Harris, member services representative for ABC Health Plan, on October 8, 20XX, and asked for the specific reasons the request was not honored. She said that in my policy, Section 22, that our benefits only cover 20 visits per year. But, there is another paragraph in the same section that says that additional visits may be covered when medically necessary and with specific recommendation from a medical doctor.

I am enclosing the original two requests from our doctor recommending additional visits, a letter from Georgia Star, a physical therapist at the neuro-developmental center in our area, and an article from a June, 20XX medical journal that supports our request for you to change your decision and pay for additional physical therapy for my son.

According to the guidelines for filing an appeal that were sent to me, I should get an answer within 30 days. I will expect your answer no later than November 25, 20XX. My address is 123 Elm St., Seattle, WA. 7

While waiting for your answer we will continue physical therapy services since Washington law gives us that option.

Sincerely,

Susan Jones

10 cc: Dr. Ed Moss,
Georgia Star
C.R. House, State Insurance Commissioner

8 Resources

Washington families of children with special health care needs have many resources they can use to help their child and family get better services and quality of life. Many families say it is sometimes hard to find these resources! Below is contact information including phone numbers, web sites and brief descriptions of some of the resources in our state. We hope that this list will help you find what you need for your child and family.

HEALTH CARE COVERAGE IN WASHINGTON

Medical Assistance Administration (MAA)
(900) 659-7000
(800) 562-3022
(TTY/TDD (800) 848-5429) Toll free
Web Site: http://maa.dshs.wa.gov/

MAA is part of the Washington Department of Social Services and Health (DSHS). It oversees two important health care options for children with special needs and their families. You may get information about Healthy Options and Children's Health Insurance Program (CHIP) from the MAA Customer Service Center at the toll-free number shown at left.

Healthy Options
(800) 562-3022

Healthy Options is the name of Washington's Medicaid program that provides health care coverage to eligible low income families, pregnant women, and children under 19. People in Healthy Options don't pay monthly fees and co-payments.

Children's Health Insurance Program (CHIP)
(800) 562-3022
Web Site: http://maa.dshs.wa.gov/CHIP/Index.html

Beginning in February, 2000, uninsured children under 19 may be able to get health care coverage through CHIP if they don't qualify for Healthy Options but still meet certain other guidelines, including income level. Call MAA or the Ask Line to learn about specific requirements. Families whose children qualify for CHIP pay small monthly fees and co-payments.

Washington Basic Health Plan
(800) 826-2444
Web Site: http://www.wa.gov/hca

The Basic Health Plan is open to any Washington resident except people who qualify for Medicare or live in an institution. Costs are based on your income, the number of people in your family, and which plan you choose. Additional benefits are available for children under 19, under the Basic Health Plan Plus option.

HELP WITH QUESTIONS AND APPEALS

Washington Office of the Insurance Commissioner
(800) 562-6900 - Consumer Hotline
Web Site: http://www.insurance.wa.gov

The state insurance commissioner oversees health care and other insurance products, including managed care and fee-for-service coverage. Information is available by telephone, in written materials, and through their Internet web site. A group of trained volunteers, called Statewide Health Insurance Benefits Advisors (SHIBA) provide a wide range of information about health care plans and coverage. They also manage insurance complaints.

Statewide Health Insurance Benefits Advisors (SHIBA) Helpline
(800) 397-4422

A free public service of the Washington State Insurance Commission that gives information about health insurance, including your rights, options and tips to help you make informed choices.

State Legislator

Look in your telephone book under **State Government** to find the number for senators and representatives in your district.

PARENT MATCHING AND FAMILY SUPPORT

Often, parents get the best resource information from other parents! Talking with other parents may help you learn about more resources than we can list here. It may also put you in contact with other families who can listen and offer encouragement. Statewide parent organizations that can link you with other families are:

Family Support Opportunity Program

See listing on page 55 under **State Agencies and Programs.**

Washington State Parent to Parent
(425) 641-7504
(800) 821-5927 Toll free
Web Site: www.arcwa.org

Washington State Fathers Network
(206) 284-2859
Web Site: www.fathersnetwork.org

Ethnic Outreach and Parent Support
(800) 821-5927 for referrals

Parent to Parent Power
Serving Asian Parents
(253) 531-2022

TELEPHONE INFORMATION

Washington State Operator
(800) 321-2808 toll free

This is a state information line that will provide you with telephone numbers for Washington State agencies. The operator can help you figure out which state agency you need to call.

ASK Line (Answers for Special Kids)
(800) 322-2588 (Voice) toll free
(800) 833-6388 (TTY)

This line offers help finding health care and other information for your child; many languages are spoken.

Healthy Mothers/Healthy Babies Hotline
(800) 322-2588

This hotline provides information on resources and service networks for families and children both statewide and at the local level. Assistance is available in English, Spanish and other languages as needed. It connects families to local Family Resources Coordinators and other resources, including CHIP and other insurance options.

Children's Resource Line at Children's Hospital and Regional Medical Center
(877) 526-2500 toll free
(206) 526-2500

Children's Hospital and Regional Medical Center offers assistance to families around the state, even if your child is not a patient there. You can get free and confidential service. Information is available on child health and illness, specific diseases, parenting, and resource information.

RESOURCE BOOKLETS AND PUBLICATIONS

Starting Point: A Resource Guide for Families with Children with Special Health Care Needs in Washington State (2000)
Web Site: www.cshcn.org
(206) 526-2500

Children's Hospital & Regional Medical Center, together with Healthy Mothers, Healthy Babies Coalition of Washington State, developed this list of resources. It is available on the Children's Hospital web site under the heading "Resources for Parents, Children, and Families." Select the sub-menu, "Children with Special Needs." You can also call Children's Resource Line to request a copy.

Care Notebook
If you are a Washington resident, you can get a free copy by calling Moore Business Forms at:
(800) 826-9873 ext. 2910
(206) 622-0384 ext. 2910

This is a notebook to help parents collect and record their child's health history. It is very useful for organizing your child's records and remembering important events.

Library Resources for Families of Children with Special Health Care Needs
Call 360-236-3573 to get your copy.
You can also download a copy from their web site by going to: http://www.doh.wa.gov/cfh/CSHCN/libfinal.pdf

This booklet was developed by the Washington Children with Special Health Care Needs Program (Department of Health) to help families find information at their public library.

Exceptional Parent Magazine
(800) 535-1910 Toll Free
Web Site: http://www.eparent.com

A monthly magazine with articles and products for children with special needs. Each year there is a resource guide listing information, products and service sources by state.

National Maternal and Child Health Clearinghouse
(call for their catalog of materials)
(703) 821-8955

STATE AGENCIES AND PROGRAMS

Children with Special Health Care Needs Program
Washington Department of Health
Maternal and Child Health/Community and Family Health
(360) 236-3571

The Children with Special Health Care Needs Program is a federally and state funded program for children who have chronic illnesses and/or developmental delays. The program works to develop improved systems of care for children with special health care needs and their families. Staff can link you with public health nurses or other professionals in your area who can help you with health care and coordination issues. The program offers information, service coordination assistance, family leadership development around health issues, and other services.

Division of Developmental Disabilities (DDD)
(360) 902-8444 State Program Office
(800) 321-2808 (Washington State Operator for connection to the regional office nearest you)
Web Site: http://www.wa.gov/dshs/ddd/index.html

DDD is a division of DSHS with six regions in Washington State. Assistance is provided for individuals with developmental disabilities and their families. Services are available for a variety of income levels. Services include case management, early intervention, family support, residential and community support, medical services, employment and community access.

To get direct assistance from DDD, go to your regional office and request services for your child (you may be placed on a waiting list). Request an evaluation of your child's eligibility for services. Tell them if you need family support, respite, medical coverage or other services.

Family Support Opportunity Program

This program is part of DSHS/Division of Developmental Disabilities. It provides a wide range of supports to families caring for children with disabilities. Call your regional DDD office (see toll free number above) to get connected with the Family Support Opportunity Program. Eligibility is based on your child's developmental disability status, not your income. The program offers a limited amount of financial assistance for respite and other services, community guides, the CAP Waiver and other supports.

Infant Toddler Early Intervention Program (ITEIP)/For children from birth to 3
ITEIP is part of DSHS/DDD
(360) 902-8488
To locate the FRC in your local area,
call (800) 322-2588 (ASK Line).
Web Site: http://www.wa.gov/dshs/iteip/iteip.html

ITEIP programs are available through each county's Family Resources Coordinator (FRC). Any family who is concerned about their child's development (ages birth to 3) may call an FRC to see if their child can get early intervention services. FRCs help families find information about early intervention services, see if services are needed for your child, help you connect with community services and coordinate the services that your child needs.

Public Health Nurses
(State, District or County level)
(800) 525-0127 (Office of Health Consumer Assistance)

A public health nurse (PHN) helps support children and families, acts as a care coordinator, and works with families so they can become their own resource managers and advocates. Anyone can ask for the services of a public health nurse, regardless of the type of health plan or income level they have.

Each county has a public health department. Public health nurses and services for families vary from county to county. For specific county health departments, look in your telephone book in the Government White Pages under county listings for Health Centers or Health Districts.

Neurodevelopmental Centers (NDCs)
And Developmental Centers
Call your primary care provider
Or ITEIP (360) 902-8490

Neurodevelopmental centers and developmental centers offer programs and therapies for children who have developmental delays or disabilities, including important early intervention services.

If your child is in Healthy Options or Basic Health Plan Plus, Medicaid pays fee-for-service for some of these early intervention services, but only if services are delivered at certain centers. Sometimes the managed care plan will pay for early intervention services, and other times DSHS covers them. Be sure to check with your health plan about how your child's services will be paid.

If you are in a managed care plan, you will need a referral from your child's primary care provider in order to go to a neurodevelopmental or developmental center.

Community Health Clinics
Web Site: http://www.wa.gov/hca/chs/index.htm

The community health clinics represent a network of community and migrant health centers, public hospital-affiliated clinics, and local public health jurisdictions that provide many services to low-income and/or special populations with a focus on medical and/or dental care.

To find out about the community health centers in your area call 1-800-322-2588 (ASK Line) and ask about community health centers or primary care services contractors where you live.

School Health Programs - Office of the Superintendent of Public Instruction (OSPI)
360-753-6733
Web Site: http://www.ospi.wednet.edu/

NATIONAL INFORMATION

Family Voices
(888) 835-5669
(505) 872-4774
Web Site: http://www.familyvoices.org

Family Voices is a national grassroots network of families and friends speaking on behalf of children with special needs. They provide information and educational materials to families through a network of coordinators in each state.

National Information Center for Children and Youth with Disabilities (NICHY)
(800) 695-0285 (Voice/TTY)
Web Site: http://www.nichcy.org

NICHY is the national information and referral center that provides information on disabilities and related issues for children from birth to age 22. You can get information on many disability-related topics, personal responses to specific questions, referrals to other organizations and sources of help. You can also use NICHY's database of resources on their Internet web site to help find information you need.

National Organization of Rare Diseases (NORD)
(800) 999-6673
Web Site: http://www.rarediseases.org

This is a national clearinghouse for information about rare diseases and syndromes. NORD can provide information on symptoms, causes and treatments of over 1,100 rare diseases. (A rare disease affects fewer than 200,000 people in the United States).

SPECIFIC DISEASE OR CONDITION GROUPS

There are many organizations that provide support and information about specific conditions or disabilities. They can provide you with brochures and other resources. Sometimes they may be able to provide limited financial assistance for medical needs or transportation. Examples include United Cerebral Palsy Association, The Autism Society, The Arc of Washington State, and many others. You can also reach many support groups for inherited conditions through the Genetic Alliance, a national alliance of support groups, at (800) 336-4363 or through their web site at http://www.geneticalliance.org

You can find telephone numbers for local groups in the business section of the White Pages or the Community Service Numbers at the front of the White Pages under Disability/Diseases. Phone numbers may also be found in the Yellow Pages under Associations-Health, Social Services.

ADDITIONAL INTERNET WEB SITES

If you don't have Internet access at home, many public libraries or schools have computers that you can use and people who will help you get started. There are many web sites for children with special health care needs and their families. Some contain information about specific conditions. Others have current information about programs and agencies. Some help you link with other families or support groups. Still others give information about current issues or research.

Be careful when using information from Internet web sites—the quality of information varies. Check the source of the information and verify what you have read with your health care professionals.

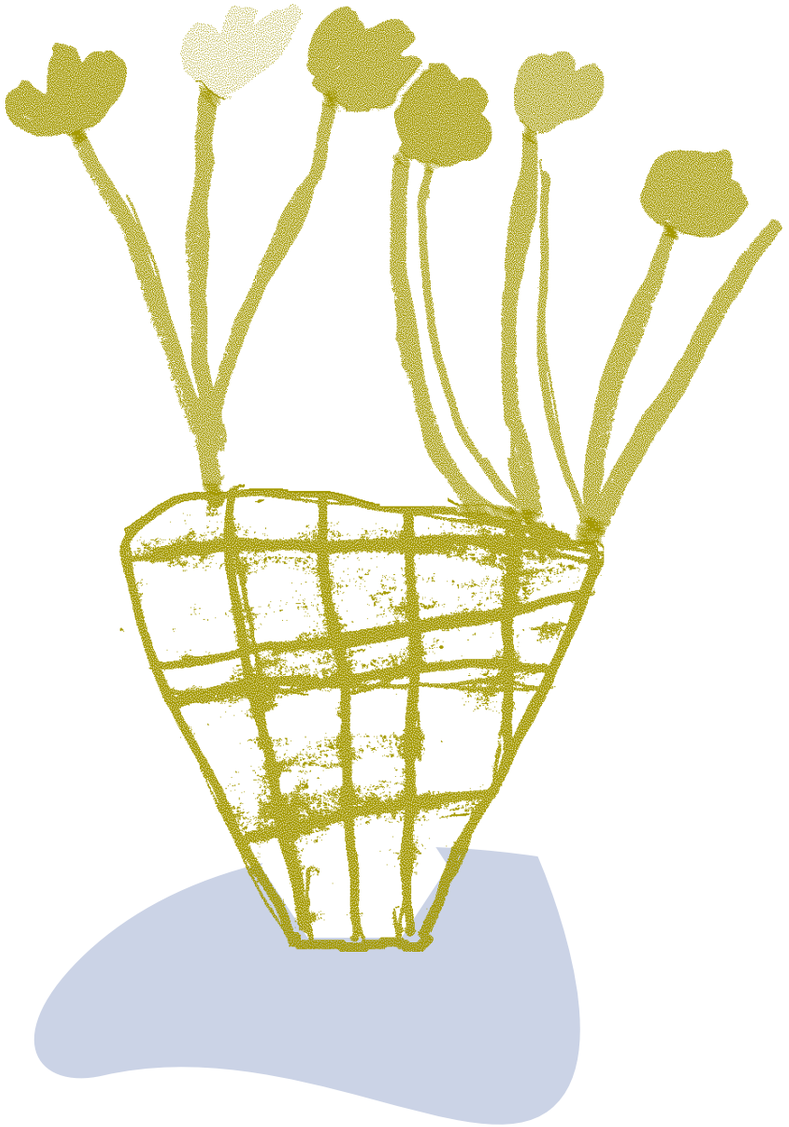
Here are some excellent sites for you to try

Parent's Guide to the Internet Web Site (tutorial)
http://www.ed.gov/pubs/parents/internet/message.html

Family Village Web Site (information and resources)
http://www.familyvillage.wisc.edu

Washington State Resources (contact information for children's disability organizations)
http://www.nichcy.org/stateshe/wa.htm

Health Pages - The ABC's of picking a Pediatrician
http://www.thehealth pages.com/articles/ar-pedia.html



9 Glossary of Useful Managed Care Words

KEY TERMS

It is important to understand the words used in managed care in order to get the most from your benefits and get the care your child needs. Here are some insurance and health care terms with their meanings to help you navigate the system.

Appeal
An appeal is a letter you write that asks a health plan to change a decision. See the sample letter on page 47 (see "Complaint or Grievance Procedure" in this glossary).

Benefits or Benefit Package
Health care services covered by a health plan or health insurance company, under the terms of its member contract.

Capitation Rate
Amount paid to a health plan or provider for services based on a fixed monthly or annual amount per person, no matter how many services are used.

Case Manager/Care Coordinator
A staff member of a health plan or other agency that helps to get, organize and follow up on health services for people who have extra or complicated needs. Ask if there is a case manager or care coordinator at your health plan or hospital.

Complaint or Grievance Procedure
Process in a health plan for people to use when they don't agree with a decision about referrals, services, billings, or other policy decisions.

Coordinated Care

Health care and services that are planned and carried out among a team of providers, including primary care doctors, specialists and family members. Coordinated care is based on good communication and working as partners to be sure that all needs are met, there are no gaps in service, and the same services aren't being given by different providers ("duplication of service").

Co-payment

The amount paid by a managed care member for each visit or for each prescription . The amount is usually $5 or $10. At this time Healthy Options members in managed care do not pay co-payments.

Covered Services

Services listed in a health policy that a health plan agrees to pay for and/ or provide.

Deductible

The amount that you are required to pay for health services before insurance pays. Usually a feature of fee-for-service insurance plans, not commonly used in managed care.

Developmental Delay or Disability

Overall development or any type of skill that is lower than what is usually expected for children in the same general age group. Mental retardation is one type of developmental disability.

Documentation

Written records relating to your family's medical care and insurance. You may need detailed records to support your case if you disagree with your insurer.

Durable Medical Equipment (DME)

Equipment that is used for a long time and not thrown away (wheelchairs, ventilators, braces, etc.). Non-durable equipment is thrown away (gloves, catheters, diapers, etc.).

Emergency Care

The immediate care that is necessary when someone has a condition, illness, or injury that is life threatening or would significantly impair his/ her health.

Employer Contribution

The amount of money an employer (the company you work for) pays towards the health benefit plan for its workers.

Exception to Policy

Agreement from a health plan or managed care organization to provide and pay for a service, medicine, or method of treatment that is not listed as a covered benefit. It is a good idea to have exceptions to policy in writing.

Exclusions (also referred to as Limitations)

A treatment or service that is not covered by a policy, or that is covered for a limited number of visits or a specific period of time.

Explanation (of denial, limit, or delay)

The reason that a request is turned down. If you ask for an explanation of why a decision was made, ask that it be written in language you understand, that it tells you specifically which part of your policy or benefits do not support your request, and how you can appeal the decision.

Family Centered Care

Health care that focuses on the family, its strengths, needs and beliefs. Family centered care recognizes that family members are the "constant" in a child's life and serve as the child's best advocate. In family centered care, families are respected and work with professionals as a team.

Fee-for-Service

A form of health coverage that requires payment for each service, supply, prescription or piece of equipment. Fee-for-service is very different from managed care where a fixed payment or premium is paid whether or not services are used.

Formulary

List of approved prescription medicines which health plans pay for. A formulary may include generic (no name) drugs instead of brand name drugs. You may have to pay all or part of the cost if you ask for medicines not listed in the formulary.

Health Maintenance Organization (HMO)

A type of managed care plan that requires enrollees to receive all of their care from doctors in its own network. An HMO offers a specific list of health services for a fixed monthly fee (capitated rate) and sometimes a small fee for each visit or service (co-payment).

Healthy Options

Washington's Medicaid program that provides health care coverage to eligible low income families, pregnant women, and children under 19.

Managed Care

A system of health care that works to control medical costs by using certain providers, focusing on health and prevention, avoiding duplication, and managing routine and specialty care through a primary care provider. In managed care, people within a plan are called members. Payment for most services is through monthly premiums and small co-payments at the time of each visit, instead of a fee for each provider and each service.

Managed Care Organization

The corporation or company that runs a managed care plan.

Managed Care Representative

The contact person at each managed care plan who can provide you with a member handbook, annual report, copy of a recent member newsletter and results of any member satisfaction surveys. This person can also assist with some questions about health care coverage and services within a specific plan.

Medicaid

Federal Program that pays for health services for certain groups of people. The program is funded with federal and state funds. In Washington, it is run by the Medical Assistance Administration (MAA) and the managed care plan is called Healthy Options.

Medical Assistance Administration (MAA)

MAA oversees the Medicaid program in Washington, Healthy Options. It also administers the Children's Health Insurance Program (CHIP) and other health care programs.

Medically Necessary

Services needed to prevent harm to the patient or the patient's quality of life. A health plan may have a very specific meaning for this term. Find out how the health plan you want to join or are already in defines "medical necessity" or "medically necessary" services.

Network of Providers

The list of primary care providers and specialists who have written agreements with a health plan.

Out-of-Pocket Costs

All the health expenses that you must pay with your own money, including deductibles, co-payments and charges not covered by any health plan.

Pediatric

Having to do with children. A pediatric specialist is someone who has had extensive training and experience in children's health care.

Point-of-Service Health Plan (POS)

A health plan that lets you choose from a network of providers or from providers outside its network. When you use network providers your benefits are greater and your out-of-pocket cost is smaller. When you select out of network providers, a point of service plan is like fee-for-service and you may have to file a claim and pay a larger part of the cost.

Preferred Provider Organization (PPO)

A type of managed care that covers services received from network providers and also lets you select providers who are not part of their network if you pay a higher co-payment or a bigger part of the cost.

Primary Care Provider (PCP)

Health provider who works with a family or individual person to make decisions about care and referrals. A PCP may be a doctor or other health professional. It is better to actively choose your child's PCP than to wait to be assigned one.

Prior Authorization

A way to control medical costs by requiring a service or medication be approved before the actual visit or purchase. Each health plan has its own rules about how and when prior authorization (approval) is needed.

Purchaser The employer, state, federal government or individual who buys the benefits contained in a health insurance or managed care plan.

Referral The written order that authorizes a patient to receive care from a specialist, therapist, or a hospital. Most MCOs require a referral from the member's primary care provider and also a prior authorization from the MCO in order for specialty care to be paid.

Specialist A doctor whose training focuses on a particular area beyond the general training required for all doctors.

Sub-network A group of providers within a network who have organized and may have additional agreements or their own guidelines about services and payments.

ACRONYMS

One of the challenges you may face along the way is the jargon that is often used in health care. Here is a list of some common managed care and agency acronyms used in Washington. An acronym is a shortened version of a group of words. For example, a primary care provider is sometimes called a PCP.

ADA Americans with Disabilities Act

ARNP Advanced Registered Nurse Practitioner

CHDD Center on Human Development and Disability at the University of Washington

CHIP Children's Health Insurance Program

CSHCN Children with Special Health Care Needs

DD	Developmental Disability or Developmental Delay
DDD	Division of Developmental Disabilities
DME	Durable Medical Equipment
DO	Osteopathic Doctor
DOH	Department of Health
DSHS	Department of Social and Health Services
EI	Early Intervention
EPSDT	Early and Periodic Screening for Diagnosis and Treatment
FRC	Family Resources Coordinator (Birth to Three)
HMO	Health Maintenance Organization
HO	Healthy Options (Medicaid Managed Care)
IDEA	Individuals with Disabilities Education Act
ITEIP	Infant and Toddler Early Intervention Program
MAA	Medical Assistance Administration
MCO	Managed Care Organization
MCP	Managed Care Plan
MD	Medical Doctor

NP	Nurse Practitioner
OSPI	Office of the Superintendent of Public Instruction
PA	Physician's Assistant
PCP	Primary Care Provider
PHN	Public Health Nurse
POS	Point-of-Service Health Plan
PPO	Preferred Provider Organization
SSA	Social Security Administration
SSI	Supplemental Security Income
TDD	Telecommunications Device for the Deaf
TTY	Telecommunications Typewriter
(WAC) 388-538-110	Washington Administrative Code 388-538-110 protects your right to keep services going when appealing a decision
(WAC) 388-538-120	Washington Administrative Code 388-538-120 guarantees you right to obtain a second opinion.

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June 2000

Washington State Department of Health

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Health Education Resource Exchange Web Team

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