

DISABILITIES— TWO CAUSES ARE 100% PREVENTABLE

FETAL ALCOHOL SPECTRUM DISORDERS

One of the effects of drinking alcohol during pregnancy can be Fetal Alcohol Spectrum Disorders (FASD).

FASD, a lifelong condition that causes physical and intellectual disabilities, is characterized by growth deficiencies and central nervous system (CNS) problems.
NO AMOUNT OF ALCOHOL IS SAFE DURING PREGNANCY; NOR IS THERE A SAFE TIME TO DRINK DURING PREGNANCY

SHAKEN BABY SYNDROME

Shaken Baby Syndrome occurs when adults, frustrated and angry, shake a child.

A baby's neck is too weak to support their head. When shaken, their head flops back and forth, causing serious brain injury. A baby's brain and the blood vessels connecting the skull to the brain are fragile and immature.

IT IS NEVER OK TO SHAKE A BABY. PUT THE BABY DOWN IN A SAFE PLACE AND WALK AWAY UNTIL YOU COOL DOWN



TO LEARN MORE ABOUT HOW PARENT TO PARENT HELPS FAMILIES OF INDIVIDUALS WITH DISABILITIES CALL 800-305-8817 OR / OUR WEBSITE www.parenttoparentnys.org

FACT SHEET ON DOCTOR SELECTION

How to Choose the Right Physician

Choosing the right doctor is a very important decision. Yet, many people take more time to compare the quality and price of their next car than they do to select a physician.

Today, many people have primary care physicians who serve most of their needs and can refer them to specialists when necessary. Primary care physicians generally include internists, family practitioners, pediatricians and, in some instances, obstetricians and gynecologists.

How do you select a primary care physician, and how do you know if the specialists he or she suggests are the right doctors for you? Here are some things to consider when selecting a physician:

- Ask friends and relatives for recommendations. If you are moving and changing physicians, ask your current physician if he or she can refer you to someone in your new community.
- Check with area hospitals. Many of them offer referral services.
- Check with your county medical society. They will give you the names of several physicians.
- Ask your insurance company, health maintenance organization or managed care plan if they have a panel of physicians from which you should select.
- Contact your regional Parent to Parent office to locate parents in the area you are moving to. They can be a good resource to learn about new doctors.
- Once you have the names of several physicians, you can do some additional checking to help you make a final decision.
- Set up a time to interview potential physicians. Most offices will set aside 15 minutes for physician interviews. One question might be to ask how many people with disabilities the practice serves. Also, ask what their policy is to accommodate people with disabilities, i.e. Reduced wait times, quiet waiting areas.
- Review your health insurance plan to determine if a physician you are considering using is part of your and/or your child's health insurance network or if the plan will cover "out of network" physician referrals.
- Is the physician licensed? To find out if the physician is currently licensed and registered in New York State, call the State Education Department at 518- 474- 3817 or access the department's Web site at www.nysed.gov. Education Department staff can also tell you where the physician attended medical school.
- Is the physician board- certified? Many doctors become board certified in a specialty. This means that they complete specialty training and pass formal examinations. While no guarantee of excellence, board certification is one way the average consumer can be certain of a physician's training. Many primary care physicians also are board-certified in specialty areas.
- The Directory of Physicians in the United States, the Medical Directory of New York State and The Directory of Board- Certified Medical Specialists list qualifications of individual physicians. They include where the physician attended medical school and received residency training, board certification; hospital affiliations; type of practice; and other

information. These books can be found in the reference sections of most libraries. You may also call the American Board of Medical Specialties to confirm if a physician is board-certified and to get the number of individual specialty boards. The Board can be reached at 1- 800- 776- 2378.

- How does the office operate? Check a physician's office hours and locations, payment requirements, emergency and after- hours coverage, and the availability of telephone consultations and house calls. Find out at what hospitals the physician has admitting privileges.
- What about the physician's malpractice record? Information on a physician's malpractice record must be obtained by checking with the County Clerk's office. That information is not available from any state agency.
- Has the physician been disciplined? To learn if a physician has been disciplined, call OPMC at 1- 800- 663- 6114. Or, access the medical conduct Web site at www.health.state.ny.us and select the "Disciplined Doctors" button at the top of the homepage. Only final disciplinary actions are provided. Pending or dismissed complaints are not public information.

Reporting a Problem with Your Physician

The vast majority of New York's more than 60,000 licensed physicians are dedicated, caring and capable professionals working to protect and improve the health of their patients.

The Office of Professional Medical Conduct (OPMC) and the Board for Professional Medical Conduct (the board) are responsible for investigating and adjudicating complaints against physicians and physician assistants. Each year, the Office of Professional Medical Conduct (OPMC) investigates thousands of complaints received from the public and from health care professionals and institutions. Each year, the board disciplines hundreds of physicians.

If you believe your physician or physician assistant has acted improperly, you **MUST** file a written report. You may send a letter or complete a complaint form. Your complaint should include the full name and address of the physician or physician assistant, when the problems occurred and all other relevant information. To protect your confidentiality, OPMC does not accept complaints either by facsimile (fax) or electronic mail. Please send complaints to:

New York State Department of Health
Office of Professional Medical Conduct (OPMC)
433 River Street, Suite 303
Troy, New York 12180- 2299

If you want a complaint form, or have questions, call OPMC's toll- free number, 1- 800- 663- 6114. Your complaint will be kept confidential.

Complaints against other professionals, such as dentists, nurses, chiropractors, podiatrists, optometrists and psychologists, are the responsibility of the State Education Department and should be sent to:

New York State Education Department
1 Park Avenue — 6th Floor
New York, New York 10016
1- 800- 442- 8106

What to Report

If you feel that your doctor has practiced negligently or incompetently, or has engaged in illegal or unethical practices, he/ she may have committed professional misconduct, and should be reported.

Physicians may be charged with misconduct for:

- Being impaired by alcohol, drugs, physical or mental disability.
- Abandoning or neglecting a patient in need of immediate care.
- Promoting the sale of services, goods, appliances or drugs in a manner that exploits the patient.
- Refusing to provide medical care due to race, color, creed, ethnic origin or disability.
- Guaranteeing a cure.
- Performing professional services not authorized by the patient.
- Willfully harassing, abusing or intimidating a patient.
- Ordering excessive tests or treatments.
- Failing to make patient records and X rays available to the patient or another physician on request.
- Permitting unlicensed persons to perform activities which require a license.
- Practicing the profession with a suspended or inactive license.
- Revealing personally identifiable facts, data or information without consent of the patient, except as authorized or required by law.

(For a complete list of the definitions of misconduct see Education Law Section 6530 and 6531)

What NOT to Report

Complaints regarding fees are not generally under the jurisdiction of the board unless they represent fraud. For example, it would be considered fraud if the physician charged for tests or services that were not provided. You may feel a physician charged too much for the services you received, but that does not form the basis of a misconduct action.

Complaints about a physician's communication skills, attitude or "bedside manner" are also not generally under the jurisdiction of the board. Nor does the board have any authority over such office practice issues as long waiting times or rude staff. While the board does not condone rude or uncaring behavior, such actions do not, by themselves, constitute misconduct.

How the Process Works

- Written complaints are reviewed by OPMC investigative and medical staff.
- A complaint that raises possible misconduct issues is assigned to an investigator. Typically, the complainant, the doctor and others involved in the case are interviewed. Interviews may be in person or over the phone. The identity of the complainant is confidential, although a physician may deduce the source of the complaint.
- Complaints that raise issues outside OPMC's jurisdiction are referred to the appropriate office. Complainants are notified by letter.
- If, after investigation, sufficient evidence is found, the case is presented to an investigation committee drawn from the board which can order a hearing, dismiss the matter or order non-disciplinary warnings or consultations. If the committee finds evidence of misconduct, charges are filed against the physician.
- If sufficient evidence is not found, the investigation is terminated and the case is closed. A record of the investigation remains in OPMC files for possible future reference. Complainants and physicians are notified by letter.
- Cases ordered to hearing go before another committee of the board which hears and reviews evidence from both sides. The complainant may be expected to testify at the hearing. The committee rules on the case and determines if a penalty is warranted.
- The hearing committee decision may be appealed to the Administrative Review Board which is also composed of members of the board.

Some Things You Should Know

- Only final disciplinary actions are public information. Pursuant to state law, information on previously closed complaints, dismissed actions and on-going investigations is not available to the public. Investigative files are confidential and are not disclosed to complainants or physicians.
- Because medical conduct investigations are complex, it often takes months to resolve complaints; issues that go to hearing typically take longer.
- The board cannot direct a physician to reimburse a patient, change a diagnosis or alter an opinion.
- Action taken by the board is an administrative procedure and is different than a malpractice action. Malpractice cases are heard in civil court and seek financial awards for patients or families who claim wrong-doing by a physician. The board does not initiate malpractice actions.

How to contact NYS Department of Health:

New York State Department of Health
Office of Professional Medical Conduct
433 River Street, Suite 303
Troy, New York 12180- 2299

Phone: 1-800-663-6114
518-402-0836 (main number)
Website www.health.state.ny.us
References: NYS Dept. of Health

TIPS ON HANDLING MEDICAL APPOINTMENTS

1. Find out the doctor's hours. Try to make the first appointment of the day or the first appointment after lunch.
2. Call before your appointment to see if the doctor is there and running on time.
3. Leave ample time for parking.
4. Bring extra money for parking, co-pays and lunch.
5. Find out your doctor's schedules at the Hospital and Clinic. It might be possible to schedule a few appointments in one day. This will save you money on gas, parking, childcare for siblings and reduce the number of trips to the doctor, thus making it less stressful on you and your child.
6. On a small piece of paper (the size of a credit card/business card) write or type the names, phone and fax numbers that you find yourself needing at various appointments, including pertinent doctors, labs, pharmacists, SSI numbers, ID numbers, etc.
7. Use one calendar for everything. It helps to avoid missing appointments. If you are writing appointments on different calendars you may miss something.
8. In each calendar box when you have an appointment, write down the doctor's name, address, phone number, fax number and ID number. Then, if you have to cancel or reschedule an appointment all the important information is on one page.

9. Keep a bag packed for your doctor visit at *all times*. This way in an emergency you have a toy, phone numbers, snack, drink, and medications ready and can run to the doctor's office without having to waste time looking for stuff.
10. If you think your child will need something that he or she hates or is afraid of, bring some type of reward (whether food, candy, small toy - whatever will work to calm them down).
11. Bring something for you to do while waiting - i.e. book, thank you cards.
12. Make sure the individual you have watching your other children is available to stay later in the event it takes longer than you anticipate.
13. If a hospital admission is a possibility bring your child's current medications, pajamas, favorite nighttime toy, etc. to make the transition easier. Even though the hospital will not be able to use the medications you bring, it will provide accurate information on the meds and doses.
14. Bring a small notebook to write down questions and notes about medication changes or instructions. Relying on your memory while trying to calm a child is virtually impossible.
15. Bring a note of all current medications, dosages and times given. Give the note to the doctor. It can save time and the doctor can attach the note to the file rather than write all the meds in the chart. This is also a good way to double check that what you are giving is what the doctor ordered.
16. Write down all of the questions you have prior to the appointment. It is easy to forget important questions when in the "heat of the moment".

MEDICAL PRESCRIPTION TIPS

Practical tips and questions to ask once a decision is made to prescribe a medication:

- Clarify the dose, the number of times taken daily and the name of the medication in case there is confusion on the part of the pharmacist or doctor.
- If a doctor is prescribing a 3-4 times a day medication ask if there is another prescription that is equally as effective but given only once or twice a day, thus reducing chance of forgetting to give medication;
- Indicate what type of medication is best for your child (i.e. if they cannot swallow pills request a liquid medication).
- The pharmacist will give you a print-out of side effects. Ask the doctor if there are any common or frequent side effects that you should keep an eye out for (i.e. some medications say to stay out of the sun or don't take with dairy products).
- Ask the pharmacist if there are special instructions for taking a prescription, e.g., avoid dairy for one hour, take at bedtime if a medication causes drowsiness, take before eating, etc.
- Ask if you should be taking something else with the medication (i.e. prednisone you should take calcium).
- Don't be afraid to ask the doctor for samples especially if it's a medication that you will be using for short-term use or if you are doing a trial.

- Do not change the form of any medication without speaking to your pharmacist (i.e. some medications can be crushed, chopped and mixed with juice). Always ask before altering a medication's form. Sustained release pills should not be crushed and some capsules should not be opened. Check with your pharmacist.
- If a medication tastes awful or if your child has many medications see about purchasing empty capsules and putting the medications into it so that your child won't have to taste them or swallow as many.
- Instead of leaving numerous prescription bottles on the counter of your kitchen designate a shelf in a cabinet. If there are a lot of prescription bottles, consider purchasing a three level spice rack.
- Color code bottles for each family member to make them easy to find.
- On your calendar write down the date to call a prescription and the prescription number so that you don't forget to renew it. This is critical with the 90 day mail away prescriptions since you have to wait to receive it. Some pharmacies have a monthly renewal reminder system. Inquire if your pharmacy can and will automatically renew prescriptions that are ongoing.
- If you are having difficulty with a pharmacy, request to have your insurance carrier intervene (if they are overseeing your prescription coverage).
- If your child is young and you are getting a medication in liquid form ask the doctor for extra to allow for spillage in case your child spits it out!
- Learn the brand and generic names and doses of medications your child is taking. This can help avoid prescription mistakes.
- If a refill prescription looks different than a previous supply, confirm with the pharmacist that the medication is indeed correct.

RECORD KEEPING

An important part of raising a child is keeping records of the major events in your child's life. As a parent of a child with special health care needs or a disability, this record keeping goes beyond when your daughter got her first tooth or when your son broke his arm.

Why keep records?

It is important to have medical information in one easily accessible place. Keeping track of your family's medical information can prevent unnecessary stress. If you move or change doctors, you will be able to share your medical history with the new doctor before your "official" records get forwarded.

What should I keep?

Keep all relevant information related to your child, including:

Dates of immunizations, hospitalizations, illness, surgeries

Contact info and dates of service for: doctors, specialists, dentists, surgeons, therapists, insurance companies, schools

Phone conversations logs for: medical professionals, insurance providers

Medications

Insurance information (copy of policy and correspondence)

Education/School documents (i.e. 504 Plan, notes from nurse, etc.)

Equipment, supplies and vendor information

Emergency contact information

Other information specific to your child

Where to start organizing your records?

Start with today, this month, this year. Don't let the overwhelming thought of organizing prevent you from beginning. Find a method that works for you and use it. The best method is one that you will use regularly.

Some suggestions:

File folders, accordion folders, notebooks, and a specific box or file drawer all work as locations to keep records. Find what works best for your lifestyle.

Use a different notebook, folder, drawer or box for each child.

Go through your records annually to keep them current and up to date.

FINANCIAL AID FACT SHEET

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

CARE AT HOME WAIVERS

DOH Care at Home I & II

Phone Number: (518) 486-6562

Website: http://www.health.state.ny.us/nysdoh/child/special_needs/resource_directory.htm

Eligibility criteria: For physically disabled children not eligible for Medicaid due to parents income/resources; denied Medicaid; had a 30 day hospital stay; under 18; have a physical disability according to standards in SSI; can be cared for at home at no greater cost than in an appropriate facility.

OMRDD Care at Home III, IV and VI

Phone Number: (518) 473-6256

Website: http://www.health.state.ny.us/nysdoh/child/special_needs/resource_directory.htm

Eligibility criteria: Children who have a developmental disability, complex health care needs and require Intermediate Care Facility level of care, under 18 and denied Medicaid;

CHILD HEALTH PLUS

Phone Number: (800) 698-4543

Website: <http://www.health.state.ny.us/nysdoh/chplus/index.htm>

Eligibility criteria: For all children under 19 with little or no health insurance and ineligible for Medicaid; low-income;

FAMILY SUPPORT SERVICES

Phone Number: (518) 473-7038

Website: http://www.omr.state.ny.us/hp_fss_all.jsp

Eligibility criteria: Families caring at home for family members with a developmental disability.

MEDICAID

Phone Number: (800) 522-5006

Website: http://www.health.state.ny.us/health_care/medicaid/index.htm

Eligibility criteria: Under 21, low-income (*below certain levels*) and certified disabled.

PHYSICALLY HANDICAPPED CHILDREN'S PROGRAM

Phone Number: Contact your local Dept. of Health and ask for Children with Special Health Care Needs Program Coordinator

Website: http://www.health.state.ny.us/nysdoh/child/special_needs/resource_directory.htm

Eligibility criteria: For children with a medical diagnosis with special health care needs; based on family's income and varies by county - under the Department of Health;

SOCIAL SECURITY (SSI)

Phone Number: (800) 772-1213

Website: <http://www.ssa.gov/d&s1.htm>

Eligibility criteria: Under 18, with a physical, mental impairment or combination that causes marked and severe functional limitations that can be expected to last continuously for a period of 12 months or can be expected to result in death. All SSI recipients are eligible for Medicaid. SSI is a needs based benefit and recipients must meet income and assets test to qualify.

Home and Community Based Services (HCBS) Waivers in New York State

- HCBS Waivers provide services and supports to children and adults with long-term needs and their families to enable them to remain at home and in the community.
- Waiver services are designed for people who, but for these services, require the Level of Care provided in a long-term care facility.
- Waiver services allow Medicaid to pay for some services not provided through "regular" Medicaid, such as case management, respite and home adaptations.
- Under the HCBS Waivers, parental income and assets are not considered when determining the child's eligibility for Medicaid. Only the child's income and assets are counted.
- Although the Medicaid funding obtained only applies to the child, it can be used to defray the costs of caring for the child at home.
- Waiver funding is 50% Federal dollars and 50% State or in some cases partially funded by Counties.

NYS has several types of waivers that serve children with long-term care needs:

Care at Home Waiver for Children with Developmental Disabilities

NYS Office of Mental Retardation and Developmental Disabilities (OMRDD)

Program Goal: To provide medical assistance to families with children living at home who have severe disabilities or medical conditions.

To be eligible a child must be under 18 years of age; have a developmental disability; demonstrate complex health care needs; be eligible for the level of care provided by an intermediate care facility; not be hospitalized; and be ineligible for Medicaid. Contact your local Developmental Disabilities Services Office (DDSO), Care at Home Waiver Coordinator.
Website: www.omr.state.ny.us

Care at Home Programs for Children with Physical Disabilities

NYS Department of Health (DOH)

Program Goal: To assist families in caring for their physically disabled children in the home setting.

To be eligible a child must be under 18 years of age; be declared physically disabled according to standards in the Social Security Act; have been hospitalized or in a skilled nursing facility for 30 consecutive days; be able to be cared for at home safely, and at no greater cost than in the appropriate facility.
Contact your local County Department of Social Services, Care at Home Coordinator.

Home and Community Based Services (HCBS) Waiver

NYS Office of Mental Retardation and Developmental Disabilities (OMRDD)

Program Goal: To enable persons with developmental disabilities to obtain the supports and services needed to obtain his or her goals in life. A person's independence and inclusion in the community are the primary concern in designing this package of supports and services.

To be eligible a person must have a documented developmental disability; have needs comparable to a person residing in an Intermediate Care Facility; be enrolled in Medicaid*; and live in either a Family Care home, their own, an Individual Residential Alternative, or a Community Residence.

*Children under the age of 18 may not have Medicaid upon application for enrollment in the waiver. The local Developmental Disabilities Services Office (DDSO) will provide guidance for how to apply.

Website: www.omr.state.ny.us

HCBS Waiver for Children and Adolescents with Serious Emotional Disabilities

Program Goal: To provide services and support children and adolescents with serious emotional disturbances and their families to enable them to remain at home and in the community.

To be eligible a child must be under 18 years of age; have serious emotional disturbances; demonstrate complex health and mental health needs; require or be at imminent risk of needing psychiatric inpatient care; have service and support needs that cannot be met by one agency/system; have a consistent and viable living arrangement with family that is able and willing to participate in the waiver; and be eligible for Medicaid.

Contact the Bureau of Children and Families in the NYS Office of Mental Health at 518-474-8394.

Traumatic Brain Injury Waiver (TBI)

To be eligible for this program a person must be diagnosed with TBI or a related condition; be eligible for nursing facility level of care, enrolled in Medicaid, and be between 18 and 64 years of age, and injured after the age of 18.

Contact the NYS Department of Health at www.health.state.ny.us

What is Medicaid?

Medicaid is a program for New Yorkers who can't afford to pay for medical care.

How do I know if I qualify for Medicaid?

You may be covered by Medicaid if:

- You have high medical bills.
- You receive Supplemental Security Income (SSI).
- You meet certain income, resource, age, or disability requirements.

How do I apply for Medicaid?

You can apply for Medicaid in any one of the following ways: Write, phone, or go to your local department of social services.

In New York City, contact the Human Resources Administration by calling (718) 557-1399. Residents of the five boroughs of New York City may call toll free at 1-877-472-8411.

Pregnant women and children can apply at many clinics, hospitals, and Prenatal Care Assistance Program (PCAP) offices. Call your local department of social services to find out where you can apply.

If you are in a facility operated by the New York State Office of Mental Health, contact the patient resource office.

If you are in a facility certified by the New York State Office of Mental Retardation and Developmental Disabilities, contact the revenue and reimbursement office.

When I go for my application interview, what should I take with me?

- Proof of age, like a birth certificate
- Proof of citizenship or alien status*
- Recent paycheck stubs (if you are working)
- Proof of your income from sources like Social Security, Supplemental Security Income (SSI), Veteran's Benefits (VA), retirement
- Any bank books and insurance policies that you may have
- Proof of where you live, like a rent receipt or landlord statement
- Insurance benefit card or the policy (if you have any other health insurance)
- Medicare Benefit Card

***NOTE:** Medicaid coverage is available, regardless of alien status, if you are pregnant or require treatment for an emergency medical condition. A doctor must certify that you are pregnant or had an emergency, and you must meet all other eligibility requirements.

If I think I am eligible for Medicaid, should I cancel any other health insurance I might already have?

No. If you currently pay for health insurance or Medicare coverage or have the option of getting that coverage, but cannot afford the payment, Medicaid can pay the premiums under certain circumstances. Even if you are not eligible for Medicaid benefits, the premiums can still be paid, in some instances, if you lose your job or have your work hours reduced. If you need help with a COBRA premium, you must apply quickly, to determine if Medicaid can help pay the premium.

You may be eligible for the Medicare Buy-in Program. This program pays your Medicare premiums and deductibles.

If you have Acquired Immune Deficiency Syndrome (AIDS), Medicaid may be able to help pay your health insurance premiums.

If I can't leave the house, can I still apply?

Yes. Call your local social services office and ask how this can be done.

How do I know if my income and resources qualify me for Medicaid?

The chart below shows how much income you can receive in a month and the amount of resources you can retain and still qualify for Medicaid. The income and resource levels depend on the number of your family members who live with you.

2007 Income & Resource Levels*

Number in Family	Monthly Net Income	Resources
1	\$700	\$4200
2	\$900	\$5400
3	\$1100	\$6600
4	\$1109	\$6650
5	\$1117	\$6700
6	\$1134	\$6800
7	\$1275	\$7650
8	\$1417	\$8500
For each additional person, add:	\$142	\$850

Income and Resource Levels are subject to yearly adjustments.

You may also own a home, a car, and personal property and still be eligible. The income and resources of legally responsible relatives in the household will also be counted.

Can I be eligible for Medicaid even if I make more money than the chart shows?

Yes, some people can. Pregnant women and children can have higher income levels and no resource limits.

Pregnant women, children, disabled persons, and others may also be eligible for Medicaid if their income and/or resources are above these levels and they have medical bills. Ask your Medicaid worker if you fit into one of these groups.

If an adult has too much income and/or resources and is not eligible for Medicaid, that person may be eligible for:

- Family Health Plus or
- Family Planning Benefit Program

Expanded Income levels for Children and Pregnant Women

- Infants to age one and pregnant women - 200% of the federal poverty level.
- Children age 1 through 5 years - 133% of the federal poverty level.
- Children age 6 through 18 years - 100% of the federal poverty level.

Monthly Income Effective January 1, 2007*

Number in Family	100% FPL**	133% FPL**	200% FPL**
1	\$851	\$1132	\$1702
2	\$1141	\$1518	\$2282
3	\$1431	\$1904	\$2862
4	\$1721	\$2289	\$3442
5	\$2011	\$2675	\$4022
6	\$2301	\$3061	\$4602

Monthly Income Effective January 1, 2007*

Number in Family	100% FPL**	133% FPL**	200% FPL**
7	\$2591	\$3446	\$5192
8	\$2881	\$3832	\$5762
For each additional person, add:	+\$290	+\$386	+\$580

* Income Levels are subject to yearly adjustments.

** FPL = Federal Poverty Level

If a child has too much income and is not eligible for Medicaid, the child may be eligible for Child Health Plus B.

What are my rights?

If you wish to apply for Medicaid, contact the local department of social services. Generally, local districts must determine if you are eligible and send a letter notifying you if your application has been accepted or denied within 45 days of the date of your application. If you are pregnant or applying on behalf of children, the local district has 30 days from the date of your application to determine if you are eligible for Medicaid. If you are applying and have a disability which must be evaluated, it can take up to 90 days to determine if you are eligible.

If you are dissatisfied with a decision made by the local social services district, you may request a conference with the agency. You may also appeal to the New York State Office of Temporary and Disability Assistance and request a Fair Hearing.

How do I request a State fair hearing?

You can ask for a fair hearing by:

1) Telephone: You may call the state wide toll free number: 800-342-3334; **OR**

2) Fax Number: (518) 473-6735; **OR**

3) On-Line: Complete and send the online request form at:

<http://www.otda.state.ny.us/oah/forms.asp>; **OR**

4) Write: to the Fair Hearing Section, New York State Office of Temporary and Disability Assistance, P.O. Box 1930, Albany, New York 12201.

Can I still keep part of my income if I am in a nursing home (Residential Health Care Facility) or in an intermediate care facility for the developmentally disabled?

Yes. Under Medicaid you are allowed to keep a small amount for your personal needs. You can also keep some of your income for your family if they are dependent on you. A spouse who remains in the community may also keep resources and income above the levels shown.

Will there be a lien (legal claim) placed on my estate (my assets) when I die?

If you receive medical services paid for by Medicaid on or after your 55th birthday, or when permanently residing in a medical institution, Medicaid may recover the amount of the cost of these services from the assets in your estate upon your death.

What health services are covered by Medicaid?

In general, the following services are paid for by Medicaid, but some may not be covered for you because of your age, financial circumstances, family situation, transfer of resource requirements, or living arrangements. Some services have small co-payments. These services may be provided using your Medicaid card or through your managed care plan if you are enrolled in managed care. You will not have

a co-pay if you are in a managed care plan.

- smoking cessation agents
- treatment and preventive health and dental care (doctors and dentists)
- hospital inpatient and outpatient services
- laboratory and X-ray services
- care in a nursing home
- care through home health agencies and personal care
- treatment in psychiatric hospitals (for persons under 21 or those 65 and older), mental health facilities, and facilities for the mentally retarded or the developmentally disabled
- family planning services
- early periodic screening, diagnosis, and treatment for children under 21 years of age under the Child/Teen Health Program
- medicine, supplies, medical equipment, and appliances (wheelchairs, etc.)
- clinic services
- transportation to medical appointments, including public transportation and car mileage
- emergency ambulance transportation to a hospital
- prenatal care
- some insurance and Medicare premiums
- other health services

If you are eligible for Medicaid, you will receive a Benefit Identification Card which must be used when you need medical services. There may be limitations on certain services. For you to use your Benefit Identification Card for certain medical supplies, equipment, or services (e.g., wheelchair, orthopedic shoes, transportation), you or the person or facility that will provide the service must receive approval before the service can be provided (prior approval).

What is a Medicaid managed care program?

Enrollment in a Medicaid managed care program through a Health Maintenance Organization (HMO), clinic, hospital, or physician group is available at any local departments of social services. You may be required to join a managed care plan. When you join a managed care program, you will choose a personal doctor who will be responsible for making sure all your health care needs are met. The doctor will send you to someone else if you need more help than the doctor can provide.

What does managed care cover?

Managed care covers most of the benefits recipients will use, including all preventive and primary care, inpatient care, and eye care. People in managed care plans use their Medicaid benefit card to get those services that the plan does not cover.

Do I have to join a managed care plan?

In many counties you can join a plan if there is one available and you want to. However, there are some counties where families will have to join a plan. In these counties there are some individuals who don't have to join. Please check with your local social services department to see if you have to join a plan.

Of special interest to persons with disabilities:

If you think you are disabled, and if you meet the criteria for disability included in the Social Security Act, you may be eligible for Medicaid.

If you believe you are disabled, you must furnish the local department of social services with medical evidence about your impairment(s).

It may be necessary for you to have further examinations and/or tests for the disability to be determined. The cost of such examinations, consultations, and tests requested by the disability review team, if not otherwise covered, will be paid by the local social services agency.

NOTE: Persons who are denied for reasons of failure to meet the disability criteria are entitled to appeal the disability decision that led to the denial of their application. See the section of this page entitled "What are my rights?". Any person dissatisfied with the Fair Hearing decision of the New York State Office of Temporary and Disability Assistance may also appeal to the court system.

Reference: NYS Department of Health www.health.state.ny.us

RESEARCHING HEALTH CARE INFORMATION ON THE INTERNET

Research Tips

Whereas healthcare information was once hard to come by, today we can be buried by the volume of information turned up by a single internet search. Since anybody can put anything on the internet, it is very important to sift through the search engine results carefully. Here are some tips to help parents identify quality information to assist them in making good healthcare decisions.

Types of information

- Determine if you are looking for factual information, opinions, or both.
- Factual information should be able to be verified from a primary information source which should be provided by the author.
- If the information is an opinion it should be clearly stated as such and the author should identify what qualifications put him or her in the position to be offering this opinion.

Source of Information

- Determine who owns or sponsors the website and why they are providing the information.
 - Check the domain name for your first clue
 - Web addresses that end with .gov are government owned websites; those that end with .edu are owned by an educational institution; web addresses that end with .org are generally owned by a nonprofit organization
 - .com websites are commercially driven or for profit ventures. By eliminating the .com sites when beginning a search, it significantly narrows the search down to sites that are most likely to have evidence-based information.
 - Check the website's homepage
 - If it is not immediately apparent who is behind the website's existence, try scrolling down to see if there is contact information at the bottom of the page.
 - Check sections of the website such as "Contact Us" and "About Us"

- Do not assume the website owner or sponsor is the author of the information on the website. Look for a byline or for author's information in the footer of the article or web page. You should be able to easily determine what makes the author qualified to provide the information.
- Uncover the author's purpose of providing the information. Consider the difference in perspectives of an employee paid to write the information and, for example, a customer who writes an essay about their experiences with the company's product.
- Check to see if the author's contact information is provided.

Dated Information

- Verify that each page of the website indicates when the last update was performed
- Make sure the article includes the date it was published or last updated
- Evaluate if the information is current enough for the topic you are researching.

For Further Information

- *Online Source Credibility* www.unc.edu/~briman/berry/?flushAccelerator=true
- *A User's Guide to Finding and Evaluating Health Information on the Web* www.mlanet.org/resources/userguide.html
- *How to Find the Most Trustworthy Health Information Web Sites* <http://www.canadian-health-network.ca/>
- *Tips for Health Surfing Online* www.ihealthcoalition.org/content/tips.html
- *Tutorials on Evaluating Online Information and Finding Health Information* <http://www.lib.unc.edu/instruct/tutorials.html>

SECTION 504 FACT SHEET

Section 504 is Civil Rights legislation which prohibits discrimination against people with disabilities. Children, who qualify under this law, receive services and/or accommodations in the public school system without being classified under IDEA/IDEIA and their school district's Committee on Special Education.

BASIC REQUIREMENTS

Every public school system must:

- Provide a "free appropriate public education" to each qualified person in the district's jurisdiction, regardless of the nature or severity of the person's disability and in the most integrated setting;
- Ensure that the concept of least restrictive environment is followed which means "handicapped persons must be educated with persons who are not handicapped to the maximum extent appropriate";
- Operate its programs or activities in a way that "when viewed in its entirety, it is readily accessible to handicapped persons." This program is called "program accessibility" since each unique program must be accessible. This means that every building or facility does not have to be accessible, as long as the program as a whole is accessible.

WHO IS ELIGIBLE?

Students whose illness, physical or mental disability substantially limits one or more life activities, such as caring for oneself, seeing, breathing, learning and walking are protected under Section 504.

Examples of students who are eligible include children with asthma, diabetes, allergies, cerebral palsy, cancer, HIV related illness, epilepsy, dyslexia, dysgraphia, spina bifida, ADD/ADHD and children with chronic health conditions.

WHAT SERVICES ARE AVAILABLE?

Required services may include but are not limited to administration of medication, intermittent catheterization, provision of services in an accessible location, testing of blood levels, use of equipment such as a tape recorder or calculator, note taking, adjusting class schedule, following a behavior management plan, testing modification, and extended time on all tests.

STEPS TO ACCESSING SECTION 504 ACCOMMODATIONS:

After the child has been tested, request for services and all relevant documents may be submitted to the Principal.

Within 30 school days of receipt of all required written information, the Principal or the Chancellor's Designee (NYC) shall:

- inform the parent in writing whether or not the student is eligible for Section 504 services
- if services are approved; prepare a written plan;
- if services are denied, notify the parents in writing about the appeal process.

IN THE CASE OF AN UNFAVORABLE DECISION

Within 10 days of receiving an unfavorable decision, a parent can request a Section 504 hearing. Section 504 hearings follow the same procedures used in IDEA/IDEIA Impartial Hearings, except that the parent has the burden of proving that the Department of Education erred in its decision. A parent may request an impartial hearing even if the parent requested an initial conciliation and did not get a favorable decision.

Looking after yourself and your family (cont')

- Raising a child with a chronic situation calls for specialist knowledge. Reading, seminars and consulting with professionals in parenting will avoid extra concerns and help in difficult decision-making. In the early stages of parenting, parents should avoid excessive reading as it is difficult to check what is relevant and the mind is already overwhelmed.
- Siblings will do well with regular special attention and paced information about their brother and sister. Back-up plans for how they can handle times of upheaval and questions from their peers will decrease anxiety.
- Remember that grandparents will be subjected to shock also. Try to reduce your expectations of empathic, helpful feedback, especially in the early stages.
- Advise family and friends of the nature and intensity of your trauma. Often they have no idea how to relate to the situation. Parents have found it useful to send information about the child's condition to others.

Checklist for getting support

- Are any symptoms described above persisting with the same intensity over time?
- Do you have consistent support from family and friends?
- Have you been able to express the depth of your emotions to someone?

Checklist for getting support (continued)

- Have you been given opportunities to express your feelings about the diagnosis?
- Do you express your feelings often?
- Do you find yourself "stuck" thinking about a particular incident during diagnosis, or word(s) used during diagnosis?
- Are there certain experiences that you can't get off your mind?
- When you look back to diagnosis or therabouts, do you think that the depth of your feelings are getting harder to manage?
- Do you spend more than 8-10 hours without adult company for more than two days in a row?
- Does your partner generally support you?
- Do you feel increasing anxiety in being able to manage your child's condition
- Have you been able to shake-off a feeling of "what's the point?"
- Do you avoid talking about your thoughts and feelings?

Resources

The book *Through Loss* (Bruce, E.J. & Schultz, C.L. 2004) may assist you to understand your feelings more. It is available from the Emotional Health Centre, Cheltenham 95537127.

INFORMATION & TIP SHEET

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When your child has been diagnosed with a disability or chronic condition.....

Overview

The diagnosis of a chronic condition or disability in a child represents a serious personal trauma for parents. Typically, parents feel isolated and question "why me, why my child?" Naturally, mothers and fathers experience a deep sense of painful grief that is often expressed very differently and at different points of time. Sometimes the loss or its extent is not as apparent to one parent. Perhaps one parent has not been exposed to as much information specific to the child, or they have been shielded from comparisons with other children the same age.

This difference in response can easily lead to misunderstandings and disconnection between partners and it is common for relationships to be under great strain. Often partners feel they cannot successfully support each other. The severe stress caused by trauma and grief can create physical symptoms: appetite change, nausea, abdominal pain, changed bowel habits, alteration to normal period pattern, headaches, dizziness, palpitations and chest pains. There may be efforts to reduce distress and find emotional relief by seeking distractions.

Overview (continued)

Research indicates that many parents will experience post-traumatic symptoms. Such symptoms include flashbacks to the words or situation surrounding diagnosis, preoccupation and fear with how the future might unfold, a feeling of not being entirely present, for instance, feeling remote from one's child or other children, friends and places. Sometimes parents feel that their bodies are on alert; things they did not worry about before now create fear. Naturally, there are difficulties concentrating.

Post-traumatic symptoms are often more evident in mothers because they are more likely to be at home isolated with their thoughts and being responsible for managing during the day. The workplace may allow fathers, but not all fathers, to avoid the intense thinking that mothers' experience. There are fathers who find that no amount of work distracts them from worrying. While trauma symptoms generally decrease over time, they can be resistant, particularly when traumatic information about one's child continues. Within this psychological climate, depression is not uncommon for parents.

Symptoms

Symptoms of depression will include a range of thoughts and behaviors including a sense of "dragging" yourself around – a difficulty facing the day, disinterest in previously enjoyed activities, quick feelings of agitation or irritation, problems relaxing, a loss of personal goals, change in appetite, feelings of helplessness, becoming locked into routines wherein you feel mindless, feelings of detachment from loved ones, sometimes hostility towards them. Of course there are degrees of depression, but you will have noticed some consistent changes in you.

Over time, generally parents move towards adapting to their child's condition – a possibility that seems impossible in the beginning! It is typical for parents to often feel that they have gone backwards. However, it is a steep learning curve. It is normal for a sense of grief in varying intensity to parallel the child's life.

Looking after yourself and your family

□ In the early period, post-diagnosis, parents need to be mindful of the trauma and the huge adaptation surrounding it. Try and guard against: too much reading, too many questions, being exposed to images that create fear of the future, or talking to individuals who are ignorant of the depth of your feelings. Pace yourself if possible. You will know when you are ready to take any next steps.

□ Try not to run out of energy and vital nutrients by eating small meals or snacks throughout the day. Keep up fluid intake. Alternate with your partner in taking short exercise.

□ Long periods of isolation with your own thoughts intensify negative thoughts and should be avoided if possible, if only broken up by talk-back shows at home or a brief walk.

□ Mothers and fathers need regular support to work through aspects of this trauma. Counseling should be considered vital to emotional and physical well-being.

Looking after yourself and your family (cont')

□ The well-being and longevity of the relationship between mother and father is the greatest asset amidst this trauma. Relationship counseling early on is vital in respecting each partner's unique approach to managing loss in their lives.

□ Suffering from continuing traumatic symptoms or depression is common. In these situations the natural chemicals in the brain have become depleted through ongoing stress. Finding relief through prescribed antidepressants or naturopathic means is crucial to well-being and healthy parenting. Medication may be short term. Some parents return to medication at different times. In tandem with counseling, parents continue to learn ways to manage.

□ Sleep deprivation is normal. As it can easily lead to depression, relentless sleep deprivation should be tackled early. Typically respite is difficult. Parents may need to alternate sleeping arrangements, usually away from the home environment. Sometimes parents find that prescribed medication or naturopathic substances help with gaining sleep when the opportunity arises.

□ Joining a support group of other parents in similar situations reduces perceptions of isolation. Discussion in these groups will normalize your feelings.

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Parent to Parent of NYS
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STRESS REDUCTION TIPS FOR PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS OR CHRONIC ILLNESS

Bury your guilt in the backyard.

Be a mother or father; not a therapist.

Reach out - parents helping other parents are powerful and healing.

Consider how your child's illness or disability impacts the family in a positive way. Examples:

Your family has become more accepting of differences.

You have met some great people who, otherwise, would not be part of your life.

Live in the present and enjoy the good times.

Keep a picture of the good times with you.

Take deep breaths regularly. Take more deep breaths.

Laughter is therapeutic.

Guilt is a self made emotion....make time for you.

Do something you enjoy doing; even if it doesn't include your family.

Recognize your family's strengths and build upon them.

COPING WITH YOUR CHILD'S SPECIAL HEALTH CARE NEEDS

Understand your feelings.

Express your emotions.

Educate yourself about your child's illness or condition.

Keep communications open.

Talk to other parents.

Focus on the strengths and goals that are achievable.

Believe in your child.

Establish routines.

Maintain your sense of humor! There is no co-pay for laughter!!

Remember that taking care of yourself is caring for your family.

Helpful websites:

www.parenttoparentnys.org

www.parenting-ed.org/handouts.htm

www.medicalhomeinfo.org

www.caringtodaymagazine.com

www.caregiver.com

Contact your regional Parent to Parent office to network with other parents.