FAMILY VOICES OF NORTH DAKOTA®

EPSDT North Dakota Health Tracks

Understanding and Supporting Children with Special Health Care Needs

US Dept of Health & Human Services/Maternal and Child Health Bureau-Grant # 11 H84MC07992-01-00 and *Department of Health/Children's Special Health Services*

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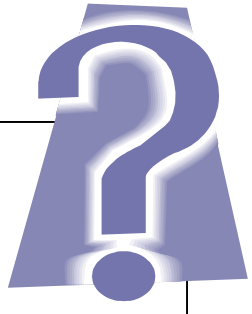
EPSDT: Helping children with special health care needs

You have a child with a disability or chronic health illness, getting adequate health care can be a very big challenge. However, for families eligible for Medicaid, there is a full children's health care benefit package called EPSDT. EPSDT stands for Early Periodic Screening, Diagnosis, and Treatment, and is a part of every state's federally required Medicaid package. In North Dakota the EPSDT program is called Health Tracks. EPSDT can be a very powerful tool in assisting children with developmental disabilities and chronic health conditions and their families to access the important services they need. If you have a child with a disability or chronic health illness, work with families, or are an advocate, this booklet has been written for you. It is very important that you know what EPSDT is, who is eligible for it, what it offers, and how to access its services. This booklet will provide much of the information you need and will also guide you to resources in your own state. Currently North Dakota receives 64.72 cents from the federal government for every dollar the state spends, on October 1, 2007 that rate will change to 63.75 cent. Through EPSDT, federal Medicaid law requires each state to provide a wide range of medically necessary services for eligible children. Compared to the majority of private health insurance plans, EPSDT provides a more robust and complete benefit package. Because EPSDT is complicated, it is often misunderstood and not used to its full potential. However, if you are well-informed, EPSDT can help you to obtain a wide range of benefits for your child, including physical and occupational therapy, personal care attendants, communication aides, and many other critical services.

We hope that this booklet will help you better understand EPSDT and Medicaid in general. It can also serve as a springboard for you and other advocates to become more knowledgeable about your state's specific policies. We'll talk about eligibility, the EPSDT process, available services, and typical areas of confusion. Every state differs in how it administers and delivers EPSDT. It is important that you first have a general understanding of the program to become fully educated about EPSDT in your own state.



Q. What does EPSDT mean for my family

A. EPSDT can provide your child with many important services such as speech pathology, physical therapy, dental care, wheelchairs, personal care aide, medical equipment, and more.

North Dakota Medicaid requires all eligible families to be informed of the benefit. This is done in a couple of ways: First, all families that fill out an application are given a Health Tracks brochure; second, every month the Health Tracks coordinator receives two printouts of all the children that are on Medicaid. This printout is broken down by county and by eligibility worker. One of these copies is sent out to the county and then distributed to each eligibility worker and the other print out goes to the regional coordinator in the area. From here phone calls are made to try to get families in for a screening or encourage them to see there primary physician.

What is Medicaid?

To understand what EPSDT is, you need to know a little bit about Medicaid. Medicaid is a program that provides health care coverage for people with low incomes, disabilities, and certain other groups that cannot afford traditional health care. Each state has its own Medicaid program which is overseen by the federal government. For every dollar that states put toward Medicaid, they will receive at least one dollar from the federal government (the average state receives $1.14 in federal money for every state dollar). In order to participate in Medicaid and receive federal money, there is a list of <u>required</u> benefits that all states must offer to all of its Medicaid recipients. These required benefits include immunizations, lab/x-ray services, hospitalization, and doctor visits. Other benefits, such as prescription drugs and personal care attendants, are <u>optional,</u> and states can choose to provide them if they wish. EPSDT is one of the <u>required</u> benefits that a state must provide through its Medicaid program. North Dakota covers children to age 21 in the Medicaid program.

Eligibility for Medicaid is not limited to "welfare" recipients. Families with moderate incomes can be eligible for Medicaid in some circumstances. The amount of income a family can have and still qualify for Medicaid varies by state. We'll provide more detailed information about eligibility later.

What is EPSDT?

According to the Centers for Medicaid and Medicare Services (the federal agency in charge of Medicaid), EPSDT is based on two principles: 1) Assuring that health care services are available and accessible; and 2) Assisting eligible children and youth to get the health care services they need.

Federal law requires that each state's EPSDT program provide a variety of health care services and preventive check-ups to ensure that children receive the treatment they need to maintain and/or improve their health. States must inform all Medicaid beneficiaries that EPSDT services are available to them. They must also reach out to families who are potentially eligible and follow up to make sure that services are being provided.

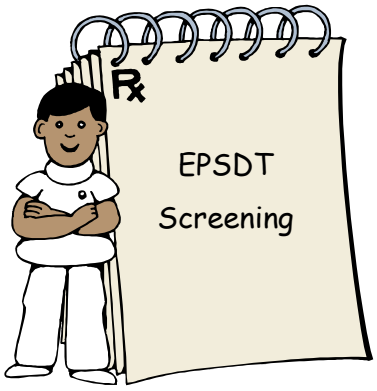
Under EPSDT, eligible children and youth are *entitled* to regular check-ups, and full physical and mental health care from birth up to age 21.

Now that you have an overview of EPSDT and Medicaid, let's look at the details of the program. In order to understand it more fully, we're going to first talk about the structure and benefits of EPSDT, and then move on to eligibility.

What Do Those Letters Stand for Anyway? E P S = Early Periodic Screening

The first three letters of EPSDT refer to the fact that eligible children are entitled to regular, comprehensive assessments of their health, or Early Periodic Screenings. These assessments (or "screenings") must include check-ups in four areas: physical health, dental health, vision, and hearing. The purpose of these screenings is to: find any problems or conditions as early as possible so that they may be treated; and ensure that children receive necessary health care on a routine basis (e.g., immunizations, ongoing monitoring of existing conditions).

Screenings address normal developmental concerns as well as signs of illness or a change in health. Your child does not have to be sick in order to be screened. Screenings also allow the rest of the process (diagnosis and treatment) to continue and be paid for by Medicaid. There are three types of screenings that a state must provide. The first kind is called an initial screen. This is a check-up that must be provided when a child enters the Medicaid program. The second type of screen is called a periodic screen (well child check-up), and should occur at regular intervals (e.g., babies get six hearing and vision screenings in the first 12 months). In North Dakota the initial screening is offered but it is not mandatory to have the initial screening (TANF families are currently the only family type that are required to come in for the screening).



Fact

Your child can have an EPSDT screening because of:
Illness
Normal development issues or a change in his or her disability/condition

By law, periodic screenings are required to include certain procedures over time, although each state can set its own timetable ("periodicity schedule") for the screenings and their components. Listed below are all the pieces required as part of a state's screening process. Most states use the schedule recommended by the American Academy of Pediatrics. North Dakota uses the Bright Futures guidelines which is consistent with AAP and AAPD guidelines. The procedures and intervals are identical to those recommended for all children.

Required Components of the Screening Process

Total health/developmental history (including a complete assessment of physical and mental health)

Complete physical exam

Immunizations

Lab tests, including tests for lead toxicity in blood

Health education/counseling

Eye exams/other vision tests

Dental services (including check ups, cleanings, and preventive work)

The third type of screen is often the most useful for many families and is called an interperiodic screen. This is a check-up or assessment that can happen at any time outside of a regularly scheduled visit. If a child shows signs of illness or a change in his/her condition, a visit to that child's doctor can count as an interperiodic screen. You can trigger an interperiodic screen by scheduling a doctor's appointment for your child. North Dakota uses the same billing code for both the initial and the interperiodic screen.

Fact

Parents can initiate the EPSDT process by requesting a doctor's appointment for their child. This visit can count as an interperiodic screen

Q: What counts as an interperiodic screen?
A: A doctor's visit because of illness or change in condition or an encounter with any Medicaid health professional (school nurse, physical therapist, etc.).

Q: Is an official referral needed for an interperiodic screen?

A: No, the referral can be made by the child, his/her parents, or any professional in or out of the health care system.

Figure 1 below gives a summary of each type of screen, and shows how all three screens fit together. Children should be screened throughout childhood, starting with an initial screen and continuing on with regular check-ups and/or screens triggered by an

Initial Screen

First check-up, either at birth or when child enters Medicaid program

Interperiodic Screen

Check-up that can happen <u>at any time</u> because of illness or a change in condition

Periodic Screen

Regular check-up that happens according to a schedule set by the state (e.g., yearly physical)

D T = Diagnosis and Treatment

Diagnosis and treatment are the "meat" of EPSDT and are triggered by screenings. Once a child is seen by his/her physician or provider and a screen reveals a problem, a diagnosis is made and an appropriate treatment can be provided.

Any illness or condition that is discovered during a screen must be treated and covered by EPSDT. Conditions do not have to be "new" to be treated.

By law, states must cover "necessary health care, diagnostic services, treatment and other measures ... to correct or ameliorate defects and physical and mental illnesses and conditions."[3] This means that states cannot refuse to provide services based on whether or not they will "cure" a condition.

If a treatment maintains a child's current condition or makes it easier for a child to live with that condition, in general it must be covered by EPSDT. For example, a child with mental retardation can receive speech therapy under EPSDT to keep from losing any current function. Once a diagnosis has been made (or confirmed, if the condition is not new), the provider can either treat the condition, or refer the child to another provider for appropriate treatment.

The five pieces of EPSDT are designed to ensure that all eligible children have access to a full range of health care services, from prevention to identification and diagnosis all the way through treatment. The law is very clear that eligible children are entitled to this care, and that states have an obligation to make sure children are consistently screened and treated as part of this entitlement.

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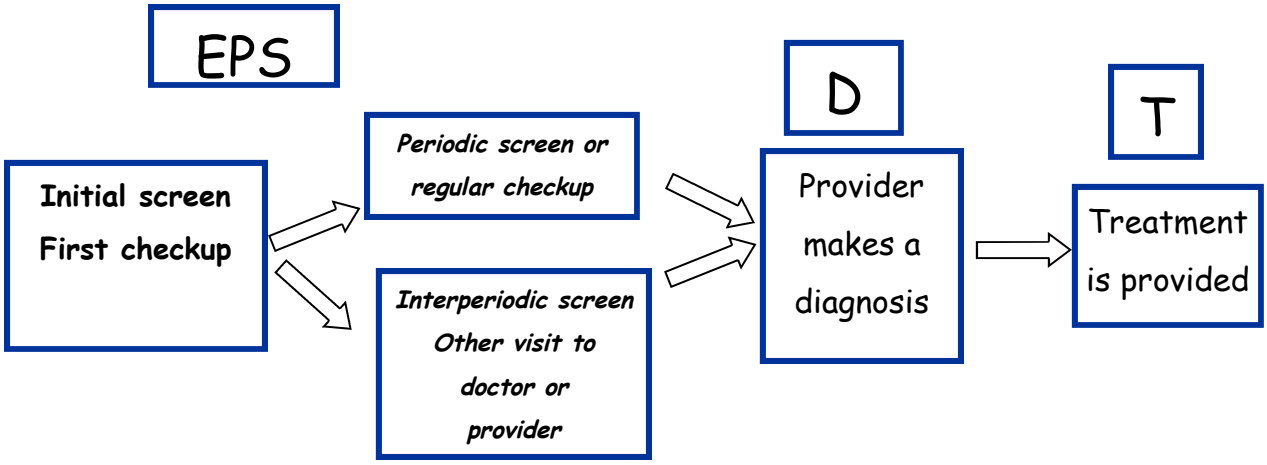
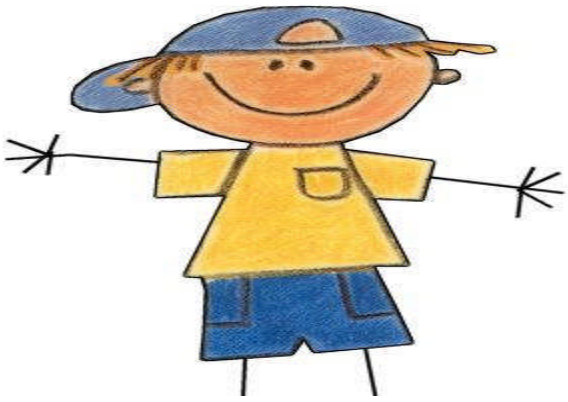
Pictured below in Figure 2 is a graphical summary of how each piece of the EPSDT process fits together.



How are EPSDT Services Delivered?

In general, states have two ways of delivering Medicaid benefits, including EPSDT. In a fee-for-service system, physicians and other providers are paid directly by the state to provide Medicaid services. North Dakota is currently using the fee for service system. If your child is in a fee-for-service state, his or her provider will probably be able to provide treatment *without* having to get prior authorization from the state. In this type of system, you select a primary care physician for your child and the physician works with you in accessing the services your child needs.



In a Medicaid managed care system, the state pays a Health Maintenance Organization (HMO) or other managed health plan to provide and manage health care benefits. In managed care plans, your child's doctor might have to get prior authorization (i.e., permission to treat and get paid) from the HMO before providing treatment. However, Medicaid HMOs still must meet all EPSDT guidelines and cover all appropriate treatments under EPSDT. Families who live in less populated areas or who are trying to obtain specialized services for their child may be told that their HMO doesn't have a provider for that service or treatment. But there is no difference between what children in managed care and those in fee-for-service are entitled to under EPSDT. Later, we will discuss grievances and appeals in the event you run into problems getting services.

What are the Requirements for EPSDT Services?

EPSDT law has certain requirements that must be met in order for a service or treatment to be administered. For a treatment to be covered by EPSDT, it must:

Be medically necessary;
Fit within a recognized Medicaid service category; and
Be prescribed and provided by a Medicaid physician/provider (i.e., one who has an agreement with the state).

Treatments Must be Medically Necessary

States only pay for services under EPSDT that are medically necessary. An unofficial definition of medical necessity is the decision by a health care or other related professional that a person's condition requires that a recognized service, intervention, or course of treatment be provided in order to address or improve the condition. There is, however, some gray area surrounding how this definition translates into specific situations.

All EPSDT services must follow Medicaid guidelines, so even if the physician says it is medically necessary they must still follow Medicaid rules for prior authorizations, transportation, etc. Always keep in mind that the regulations say it "must either correct or ameliorate defects and physical and mental illnesses and conditions." These conditions do not have to be cured. Ameliorate is defined as "to improve or become better, make bearable".

It can sometimes be difficult to convince the state Medicaid agency or managed care company that a service is actually medically necessary. However, deciding that a service is medically necessary should mainly be left to your child's treating provider (primary care physician, physical therapist, speech pathologist, or other provider). States have the right to review a provider's decision, and it is not uncommon for providers and Medicaid agencies/HMOs to disagree on what is medically necessary. However, several courts have found that states must defer to the doctor's opinion in treating patients.

Weaver v. Reagen, *886 F .2d 194 (8th Cir.* 1989) Hilburn by Hilburn v. Maher, *795 F .2d 252 (2nd Cir.* 1986) Lewis *v. Callahan, 125* F .3d 1436 (11th Cir. 1997)

You may have been told by your insurance plan that "pre-existing conditions" are not covered, or may only be covered for certain services. It is important to know that under EPSDT, all pre-existing conditions must be fully treated and cared for.

Question and Answer

Q. My son's doctor agrees that he needs a personal care attendant but my Medicaid HMO says that it doesn't cover that service. Is that true?

A: Personal care services are a required part of EPSDT, as long as they are prescribed as medically necessary by a provider. Since personal care is an "optional service" under basic Medicaid requirements, your state might not normally cover it for its adult Medicaid population. However, EPSDT requires that states cover both mandatory and optional services for children. Therefore, the HMO is required by law to cover it.

2. Treatments Must Fit within a Medicaid Coverable Service

States must provide a comprehensive set of services under EPSDT, many of which are of great importance to children with disabilities. Services covered by EPSDT fall into broad categories such as inpatient/hospital care, transportation, mental health, prescription drugs and supplies, and routine primary care. Medicaid also covers other services not relevant to this booklet, including ICF/MR, nursing facility services, prenatal care, nurse midwife services, and hospice care. EPSDT services include (but are not limited to) the following services in Chart 1.

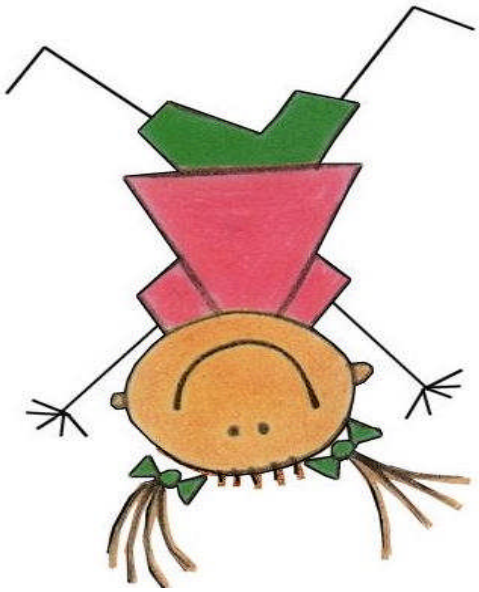


Chart 1. Services Covered by EPSDT

Hospital Services

- Ambulance to and from hospital/emergency room
- Inpatient hospital care
- Outpatient hospital care (day visits)
- Emergency room visits

Physical Health Care

- Physician/nurse practitioner services: routine check-ups, illness related visits
- Dental visits: routine check-ups/cleanings (including accommodations for children with special needs), fillings, preventive care
- Vision care: eye exams, glasses, eye drops, scratch-proof lenses
- Hearing care: hearing tests, hearing aides, cochlear implants
- Immunizations: according to established schedule
- Lab tests/x-ray services: including blood lead tests
- Podiatry care: including orthotic inserts

Mental health

- Psychiatrist visits
- Mental health therapy/counseling
- Substance abuse treatment
- Inpatient psychiatric hospitalization

Medications and Pharmacy Supplies

- Prescription drugs
- Diapers
- Special foods: diet supplements, thickeners, other foods found in a store's pharmacy section

Home/Community Services and Therapies

- Private duty nurses: nursing care in the home or community for children who require medical attention/services
- Personal care/personal assistant services: assistance with non-medical services in the home, community or school, including feeding, bathing/personal hygiene, transferring, following behavior plan
- Physical therapy
- Occupational therapy
- Speech, hearing, and language therapy (includes audiology services)
- Chiropractic services
- Nutritional services/counseling
- Some behavioral therapy: behavioral therapies for children with autism are generally covered by EPSDT, although there is some controversy about this

Supplies/Equipment

- Durable medical equipment: wheelchairs, ankle/foot/leg braces, monitors, catheters, oxygen equipment, nebulizers
- Augmentative communication devices: communication aides, optical headpointers, headsets
- Diabetic supplies: insulin pumps, glucometers, syringes

Other services

- Transportation: to and from doctors' appointments,
- Therapy visits
- Case management

While EPSDT offers a very comprehensive set of benefits, there are certain services that it will not cover. Services not covered by EPSDT are listed in Chart 2.

Chart 2. Services Not Covered by EPSDT

Respite care:

Sometimes it is difficult to distinguish between respite care and personal care (which IS covered). Respite care, though, is for the primary purpose of relieving the child's caregiver and is therefore not covered under EPSDT/ Medicaid. Personal care is covered because it is focused on the child's needs and is not intended to replace the primary caregiver.

Habilitation services:

Habilitation services are those services which help individuals acquire and/or improve social skills and basic living/adaptive skills (such as dressing, feeding, cooking). They are intended to help people reach their highest level of functioning and are not covered by EPSDT. Sometimes the line between habilitation and rehabilitation (covered by EPSDT) is not clear, and there may be disagreement over which category a service falls into. Habilitation services may be provided through a home and community-based waiver program.

Targeted case management:

Targeted case management differs from case management in that it can deal with resources and services outside of Medicaid. Under targeted case management, states can conduct assessment, care planning, referrals, and monitoring of services for Medicaid beneficiaries. Unlike other Medicaid benefits, states do not have to provide this service to children under EPSDT (although some children might receive it based on their geographic location or disability).

Treatment for another family member:

EPSDT is a child-centered program. While family members may be included in treatment insofar as they are needed (e.g., mental health family therapy that addresses how familial alcoholism is affecting the child, or parental training to administer an IV), the treatment must not be for the parent's sole benefit (e.g., respite care).

Medical Necessity and Educational Services

A special case of how EPSDT covers medically necessary services occurs in the education system – where many children receive their services. Many children with special needs receive a wide variety of services through the public school system. They range from academic services, such as reading and math instruction, to more health-related services, such as physical therapy and personal care. Trying to figure out who is responsible for paying for which services can be very confusing. However, schools can (and many do) bill Medicaid for reimbursable services under EPSDT. Medical necessity is just as important here as it is outside the school system.

According to the federal government, "Medicaid is the payer of first resort for medical services provided to children with disabilities pursuant to the Individuals with Disabilities Education Act (IDEA)."5 In other words, Medicaid-eligible children with disabilities are entitled to receive medical services in the school setting, paid for by Medicaid, if two important requirements are satisfied. First, the school/school district must be a participating Medicaid provider. Second, the services must be written into the child's IEP/IFSP, which automatically makes them considered medically necessary.

Q: My child's school says he cannot get physical therapy services at school because that is a medical service and not the school's responsibility. What can I do about this?
A: If physical therapy is a service that your child needs, it should go into his IEP. If the school says it cannot pay for physical therapy, find out if it is able to accept Medicaid payments. Medicaid can pay for physical therapy for your child at school if he is Medicaid-eligible, and it is part of his IEP. If your school is not a Medicaid provider, let them know they can be. For more information on this, see "Medicaid and School Health: A Technical Assistance Guide", available at
http ://cms. hhs.gov/medicaid/schools/scbintro.asp.

5 Letter to State Medicaid Directors from Sally Richardson, HCFA Director, May 21, 1999. Available on-line at: http://cms.hhs.gov/states/letters/smd52199.asp.

If your child is not yet school-aged, EPSDT can also serve an important function for early intervention (EI) services. Children younger than five who are considered at risk for developmental or other delays are often enrolled in a Head Start or other early intervention program.

Medicaid/EPSDT often pays for many of the early intervention services that children receive, such as developmental assessments, case management, and nutritional services. The relationship between EPSDT and EI programs is very important because any problem or issue that is detected in an EI program is treatable through EPSDT. For example, if your child's developmental assessment shows that her motor skills are delayed, she is entitled to physical therapy services to address that delay under EPSDT.

3. Treatment Must Come from a Medicaid Provider

In order for an EPSDT service to be paid for by Medicaid, the service provider must be an enrolled Medicaid provider. Be sure to check with your physician, therapist, or provider/provider agency to make sure he or she accepts Medicaid.

Beyond fulfilling these three basic requirements of getting EPSDT treatment, there are other steps you and your provider can take to assure your child receives EPSDT services in a timely fashion. Dealing with different providers and Medicaid in an effort to obtain services quickly can be challenging. It may help you to know what a provider will need in order for Medicaid (and any managed care company involved) to successfully provide services under EPSDT. The physician providing the service must also be a Medicaid provider in order for the service to be reimbursed.

> In the Medicaid world, the term "provider" can be used to mean a doctor, therapist, personal care assistant, or any other person who provides services that are paid for by Medicaid.

In order to make the process as smooth as possible, it is recommended that the following documentation accompany every health care provider's request for EPSDT services:

Physicians orders for services

Letter of medical necessity written by the physician or provider which includes:

Patient history, Diagnosis and prognosis, Description of recommended services and explanation of why they're medically necessary, what the benefit to the patient will be, and recommended length of time for the services .

Limits on EPSDT Services

States are allowed to place certain limits on EPSDT services related to medical necessity, length/duration of treatment, and how economical it is.

Medical Necessity

As previously stated, all EPSDT services/treatments are limited to those that are medically necessary to the child's health. Remember, though, that this treatment does not have to be necessary to cure or improve your child's condition, but needs to only maintain his/her current level of health

"Tentative" Limits

States are also allowed to put "tentative" limits on EPSDT treatment. However, states must also have an efficient, well-publicized process to allow children and families to receive services beyond this limit. For example, states can have a "tentative" limit of 20 outpatient mental health visits per year. But if a psychiatrist decides that it is medically necessary for a child with severe depression to have weekly visits, there must be an efficient process for the psychiatrist and family to get that approved. States may not place hard and fast limits on services that are medically necessary.

Most Economical Mode

A state can limit treatment settings and types to a less expensive or more economic setting/type of service (e.g. using medical equipment or medications that have a "generic" manufacturer rather than a brand name). However, if there is a shortage of treatment/service of a more economical mode, the more expensive version must be provided. Also, children and families must still have a sufficient choice of providers for the treatment.

Medical necessity is the decision by a health care or other related professional that a person's condition requires that a recognized service, intervention or course of treatment.

Who is eligible for EPSDT?

Sometimes people think that EPSDT has its own special set of eligibility criteria, but it does not. EPSDT is a required part of every state Medicaid plan and therefore has the exact same eligibility standards as Medicaid. Every child with a Medicaid card is eligible to receive services under EPSDT.

There are two main pathways to obtain Medicaid eligibility for a child. One pathway revolves around your household's income. If it is under the limit set by the state, your children will qualify for Medicaid (regardless of whether they have a disability). The second pathway is dependent on the severity of a child's disability and can also be affected by your family's income. No matter how a child becomes eligible, though, the same set of EPSDT benefits are available.

The most common paths to EPSDT/Medicaid eligibility are:
Standard Medicaid
Medicaid Buy-In program
DD Waiver

Overall Income Eligibility and the Federal Poverty Level

This explanation of eligibility based on household income will require that you understand a little bit about the Federal Poverty Level (FPL). The FPL is a set of income guidelines issued by the federal government each year. FPL guidelines are loosely based on consumer prices, and account for family size. The FPL is used to set income eligibility for many different public programs such as Medicaid, Head Start, food stamps, and Home Energy Assistance. You will see the FPL mentioned several times in explaining both Standard Medicaid and SCHIP. The table on the next page shows how gross monthly income translates into FPL guidelines for 2007 for all states and DC except Alaska and Hawaii.

2007 FPL Guidelines

Persons in Household	100%	200%	225%	250%
1	$10,210	20,420	22, 972	25,525
2	13,690	27,380	30,802	34,225
3	17,170	34,340	38,632	42,924
4	20,650	41,300	46,462	51,624
5	24,130	48,260	54,292	60,324
6	27,610	55,220	62,122	69,204
7	31,090	62,180	69,952	77,674
8	34,570	69,140	77,782	86,424

For each additional person, add 3,480

Standard Medicaid

Medicaid is a healthcare program for families and individuals with disabilities and/or low incomes. Under Medicaid, states must provide a basic benefits package to everyone who is eligible to participate. The program is run and paid for jointly by the states and the federal government. For low income children, eligibility for Medicaid is based on comparing the family's income to the Federal Poverty Level (FPL). Under federal law, states are required to provide Medicaid to:
Children birth through age 5 with household incomes up to 133% FPL; and
Children ages 6 to 18 in households with incomes up to 100% FPL.

These are the minimum requirements. Many states have adopted higher household income standards for Medicaid eligibility.

State Children's Health Insurance Program (SCHIP)

While Medicaid covers many of the lowest income children and families in our society, it does not cover many who still cannot afford traditional insurance. To permit states to cover children at higher income levels than Medicaid, Congress enacted the State Children's Health Insurance Plan (SCHIP) legislation in 1997. Just as with Medicaid, states commit to spending their own dollars which are then "matched" by federal funds.
Under SCHIP, states choose one of three options: expand their existing Medicaid program, design a separate SCHIP program, or combine the two approaches.

Separate SCHIP Programs:

North Dakota has a separate SCHIP program. The SCHIP program in North Dakota is called Healthy Steps. Many SCHIP programs are more flexible in their design – these programs do not have to offer the entire Medicaid benefit package. Instead, states that elect this option offer a benefit package that meets a comprehensive set of criteria. Eligibility of the SCHIP (Healthy Steps program) is at 140% of the federal poverty level. Currently SCHIP (Healthy Steps) does not have an EPSDT benefit with it but it does cover well-child exams which are not as comprehensive. For more information on Healthy Steps you may call 1-877 KIDS NOW helpline.

Obtaining Medicaid Eligibility and Other Questions

Obtaining Medicaid eligibility via the "household income" pathway requires filling out an application. Applications can be obtained through the county social service office, Family Voices of ND or download on online form at: http://www.nd.gov/eforms/Doc/sfn00502.pdf To apply, simply complete the Health Coverage Application and return it to Department 325, 600 E. Boulevard Avenue, Bismarck, ND 58505-0250. This application is used to determine if individuals qualify for health coverage under the Healthy Steps children's health insurance program or Medicaid.

The federal department of Health and Human Services has a centralized list of state eligibility and application procedures at www.insurekidsnow.gov. There you can get detailed information on how to submit a Medicaid application.

Many states have expanded their Medicaid programs so that uninsured children can access health care benefits and services. Even if your family already has health care coverage, it still may make sense to obtain Medicaid for a child with a disability. Usually, Medicaid offers a wider range of services and benefits than your private health insurance plan may offer. If you have health insurance and your child qualifies for Medicaid, the state will seek payment from your health insurance first. If it does not cover the bill, then Medicaid will pay for the service.

For children enrolled in standard Medicaid, there is no "premium" or co-payment for any services. States are only permitted to charge co-payments or premiums for children in an SCHIP program. There are three paths to Medicaid eligibility based on a child's income/disability:

- SSI
- Medicaid Buy-In
- Home and Community Based Waivers/DD Waiver/Waiver for Children with
- Extraordinary Medical Needs

SSI

SSI, which stands for Supplemental Security Income, provides a monthly stipend to individuals who have a severe disability and who meet certain income and resource (property, assets, etc.) restrictions. Children under age 18 who are SSI recipients qualify for both Medicaid and the SSI program. Some states automatically enroll SSI recipients in Medicaid. In others, children have to go through a separate enrollment process. Eligibility for SSI hinges on a) the nature and severity of a child's disability and b) in the case of children, the financial situation of the family. To meet the Social Security Administration's (SSA) disability definition, your child must have a physical or mental condition that: Results in severe functional limitations (see list of conditions at www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm) or is expected to last at least 12 months or result in death.

When a family applies for SSI, the federal government gathers information from anyone that the parent lists as having relevant input about the child's disability and the effects that the disability has on the child's life. Parents should list as many people as possible, including physicians, school personnel/teachers, other family members, therapists, etc.

Obtaining SSI also hinges on financial eligibility tests. In deciding financial eligibility for children and youth up to age 18, SSA looks at the family's income and resources (assets)[13]. SSA employs a process called deeming to assign a portion of the family's income to the child. The amount assigned to the child is then compared to the Federal Benefit Rate (FBR); in 2004, the FBR is $564. If the amount of income deemed available to the child is less than the FBR, the child is financially eligible for SSI. The deeming process is complicated. The calculations depend on the type of income the household receives, whether there are other children (with or without disabilities) in the household, and whether it is a single or two-parent household. As a result, it is not possible to provide a simple "rule of thumb" concerning the amount of household income that permits a child to qualify financially for SSI. We provide two simplified examples to illustrate the income deeming process."

> Important to note: After age 18, SSA only looks at the person's own income – not the family's – in determining financial eligibility for SSI.

Example 1

Tyler is a bright ten year-old with spina bifida who lives in Fargo with his parents and two younger sisters. His mother, Roxanne, stays at home to take care of Tyler and his sisters; his father, Tom, earns $40,000 per year as the assistant manager of an office supply store. Based on their earned income for a two-parent family and the number of non-disabled children in the household (2), the SSA deems $476 of monthly income to Tyler. This means that the family is eligible for a monthly SSI check of about $88. In addition, Tyler is eligible to receive Medicaid.

Example 2

Fifteen year-old Leah lives with her mom and younger brother in a small town in northern North Dakota. Leah has Down Syndrome and is a freshman at her local high school where she is enrolled in a special education class with other students with cognitive disabilities. Leah's mother, Tracy, earns $9.25/hour as a classroom aide. Based on the family's earned income for a single parent family and having one non-disabled child in the household, the SSA deems $34 of monthly income to Leah. This means that the family is eligible for a monthly SSI check of approximately $530. Leah is also eligible for North Dakota's program.

In addition to household income, SSA also looks at household resources (for example, money in a savings account). Certain resources, including a family's home, are not counted toward this amount. There is a process for deeming some resources to the child. As long as the amount deemed available to the child is less than $2,000, the child can qualify for SSI. Even if families are doubtful as to their child's financial eligibility, they are advised to apply, and in some cases, reapply. SSI cases are often turned down the first time only to be accepted after reapplication. A self-screening tool (not an application) is available online to help you assess whether your child might be eligible for SSI. It can be found at https://s044a90.ssa.gov/apps7/best/benefits/ . To apply for SSI, call the Social Security Administration at 1-800-772-1213.

It is not uncommon that a child might qualify for Medicaid under both "standard" Medicaid and through SSI. If the child qualifies for SSI, then there will also be a benefit payment made in addition to Medicaid services. If the child does not qualify for SSI because of household income and your state does not offer the other paths described below, then it may be possible to obtain Medicaid based on household income, depending on your state .

Home and Community Based Services Waivers

Another way that states can make children with severe disabilities eligible for Medicaid who do not qualify for SSI is to serve them in a Home and Community-Based Services (HCBS) waiver program.

Under a waiver program, a state can ignore household income in offering services to children with severe disabilities. The difference is that, in a waiver program, a state can limit the number of people served. States use HCBS waivers to provide certain services in a home or community setting to people who would otherwise need care in an institutional setting (hospital, nursing facility, or ICF/MR). Children who are covered under HCBS waivers are entitled to the normal set of Medicaid services, including EPSDT. Waivers can also provide services above and beyond what is allowable under EPSDT. For instance, respite care or environmental/home modifications may be available under an HCBS waiver, although these are not permitted under EPSDT.

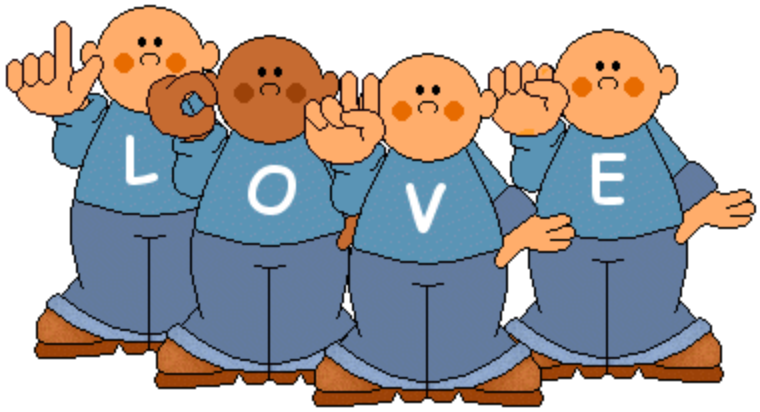
In North Dakota most waiver programs serve people with developmental disabilities. However, in the 2007 legislative session a waiver for children with extraordinary medical conditions was approved. An application to administer this waiver will need to be approved by the federal Center for Medicare and Medicaid. Information will be forthcoming soon.

Additionally in the 2007 Legislative session approval for a Medicaid Buy-In program for families of children with special health care needs was approved. A family needs to be at 200% of the FPL and the child must be SSI medically eligible to apply. The Buy-In portion means that families will need to pay a small premium for their child with a disability in order to apply. Families will need to weigh the difference in their current out of pocket expenses or the cost of the monthly premium. Information on the application process for both the waiver and Buy-In will be coming soon.

What if I'm Denied? Grievances and Appeals

Problems and complaints can come up when you have to deal with health insurance coverage, especially if your child has specialized health care needs. These could include billing issues, trouble finding an appropriate provider/doctor, or communication issues. Or a service might be denied that you feel is very important for your child. It's important to understand the proper procedure to follow in the case of a denial or other complaint.

There are a few informal steps you can take before getting into a formal complaint process. If you have general questions or concerns, the first place to start is with your child's primary care physician (PCP) or other health care provider (physical therapist, counselor, etc.). If you've spoken to your PCP and are still not satisfied, you may want to contact your HMO (or state Medicaid agency if you're not in managed care). To do this, call the toll-free number in your member handbook and be specific about why you are dissatisfied. The solution may be very easy to implement. If these informal approaches are not successful, you can move into a formal grievance process. How this process works depends on whether your child is in a managed care or fee-for-service plan.



Managed Care

If your child is enrolled in a managed care plan, your HMO must have an official internal grievance process that outlines the steps you need to follow to file a complaint, the timelines involved, and the responsibilities of the HMO throughout the process. You can use this process either to file a general complaint, or to appeal a denial of services. To get information on your plan's process:

You can call your HMO directly by using the member services phone number listed in your handbook; or

If your child has had a service denied, you will receive written notification of the HMO's internal process at the time you receive the denial.

This internal process will generally involve you detailing your complaint in writing and sending it to your HMO. They will then have a certain number of days to review your complaint and make a decision about what the outcome will be.

Fair Hearing Process

If you are not satisfied with the result of your HMO's internal grievance process, or if your child is enrolled in a fee-for-service plan, you can take your complaint/appeal through a fair hearing process. Federal law requires that all Medicaid participants have access to a fair hearing process to protect services being cut, reduced, or denied. Components of the fair hearing process include:

A written letter from the Medicaid agency/HMO notifying you if it is going to deny, reduce, or cut a service. This is in addition to any telephone or other notification you receive.
For service reductions/cuts, the letter must arrive at least 10 days before the change takes place.

For denials of new services, the letter must arrive within 30 days of when prior authorization for the service was requested.

If the written denial is not sent within 30 days, the request for prior authorization is automatically approved by default.

The letter must include instructions on how to appeal the denial/service change.

While you are appealing a reduction or cut in services, those services must continue until the appeal has been resolved.
To appeal the denial, you must respond to the Medicaid agency in writing (usually within 30 days of receiving the written denial).

This will trigger an administrative hearing, at which both you and the Medicaid agency can present your arguments. These hearings generally do not involve lawyers or other counsel. To request a hearing, you can contact your local county social service office or the State Medicaid office. For more information on appealing Medicaid decisions, please see http://www.ndpanda.org/index.html or call Toll Free: 1-800-472-2670, Phone: 328-2950

EPSDT Example

Samuel is a 9-year old boy with severe cerebral palsy. Due to his disability, he receives SSI and therefore is eligible for Medicaid. Samuel receives several services through EPSDT in a variety of settings. His motorized wheelchair, eyeglasses, and c ommunication board are all covered by EPSDT. In addition, Samuel has a bus assistant to aid him in getting to and from school each day. Samuel's school is a participating Medicaid provider, and so many of the services on his IEP are covered by EPSDT. These include two hours per week of speech and language therapy, three hours per week of physical therapy, and an aide that he shares with one other child to assist in normal daily activities. Samuel also receives 8 hours of personal care per week in his home that is provided by direct care staff from a local service provider.

What's Next?

This booklet has now given you the basic tools to being a more effective advocate for your child around EPSDT. You have been introduced to the many ways it can support your child's needs, the important pathways to Medicaid/EPSDT eligibility, the potential pitfalls and issues that you may encounter, and some possible solutions. Having this foundation is an important first step.

You have been presented with lots of information that will be much more useful to you once you know what your state's specific policies and procedures are. While we have included some -specific information around eligibility, it's up to you to become even more familiar with how North Dakota handles EPSDT. To assist you further, we've included a list of resources that may be useful. As you learn more about your state's EPSDT program, you will not only be a better advocate for your child, but can also become a great resource for other parents of children with special needs.

Resources

Health Tracks:701-328-4030, www.nd.gov/humanservices/services/medicalserv/healthtracks.

Medicaid:701- 328-2321; Toll-free: 1-800-755-2604; http://www.nd.gov/humanservices/services/medicalserv/medicaid/

Healthy Steps: Phone: 1-877-KIDSNOW (1-877-543-7669) or http://www.nd.gov/humanservices/services/medicalserv/chip/

Developmental Disabilities: Contact your local Regional Human Service office or http://www.nd.gov/humanservices/services/disabilities/dd.html

North Dakota Protection and Advocacy-Toll Free: 1-800-472-2670; Phone: 328-2950; http://www.ndpanda.org/index.html

Family Voices of North Dakota: 888-522-9654; www.fvnd.org or fvnd@drtel.net