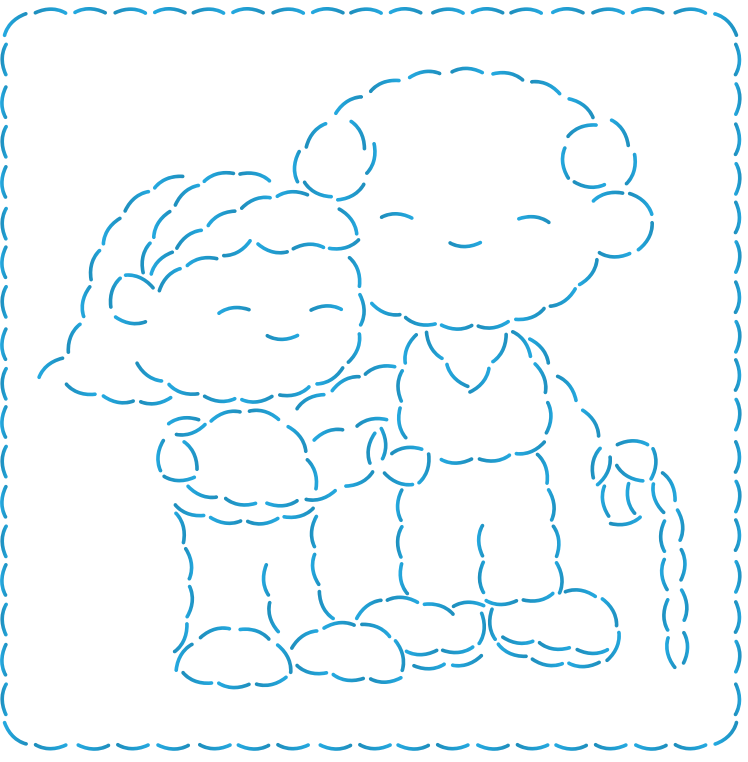
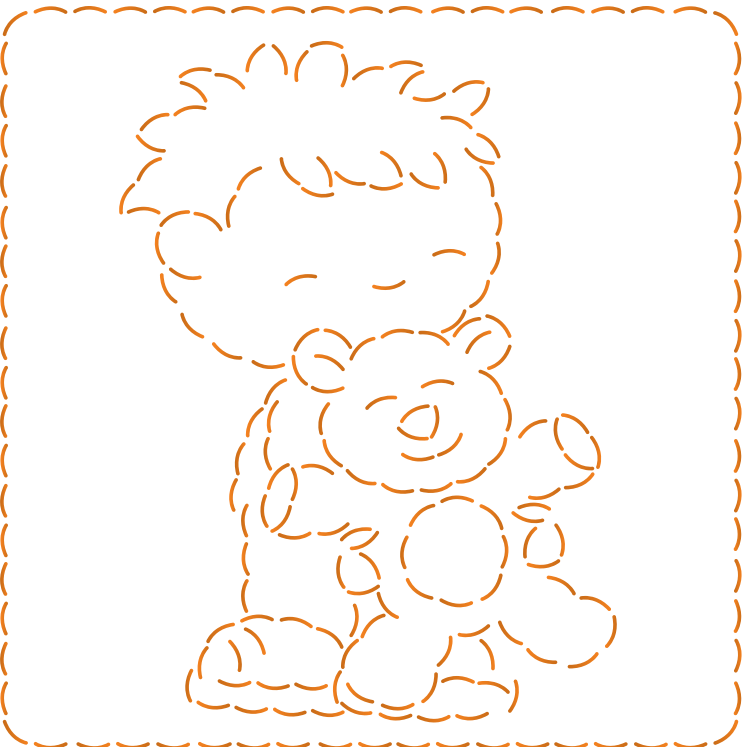
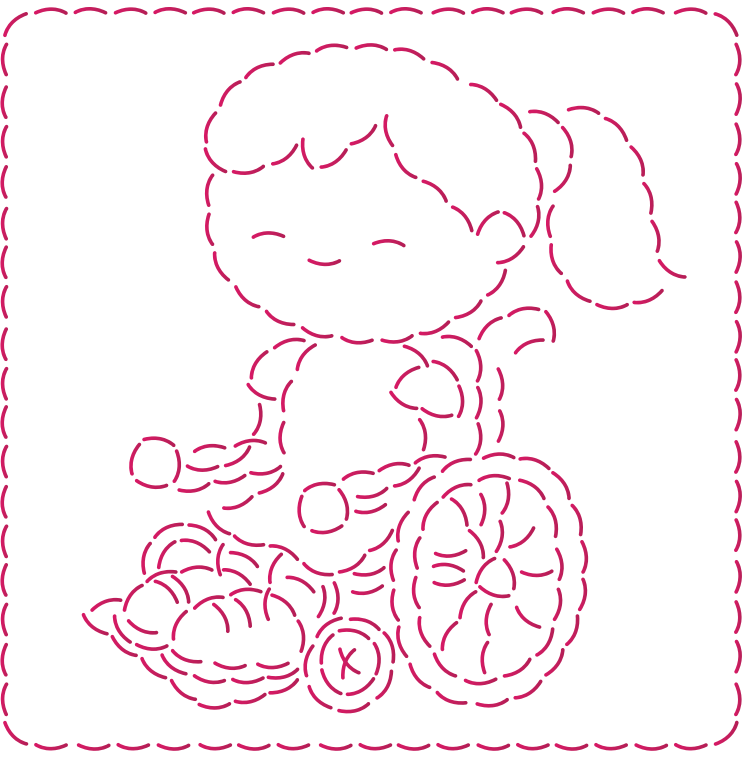
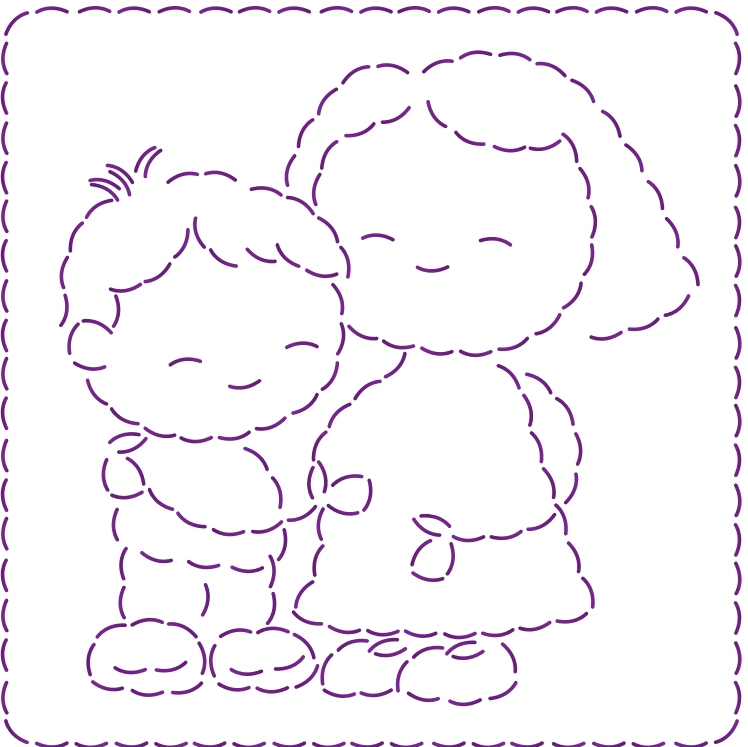


Care Coordination Notebook

FINANCING & MANAGING YOUR
CHILD'S HEALTH CARE

3RD EDITION • JUNE 2011



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The content of this document does not necessarily reflect the views of VCU, HRSA or the Department of Health and Human Services. It contains information about health insurance plans and consumer rights, but is not intended to provide legal advice. Readers in need of legal advice should consult an attorney.

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Dear Parents:

I am a parent of a child with disabilities and special health care needs, just like you! This Care Coordination Notebook was developed to help you understand the various systems with which your child might come in contact.

Many professionals will be involved in your child's life, providing assistance and their expertise. But you, as your child's parents, cannot leave the management of your child's supports and services totally in the hands of the professionals. You must become part of the team supporting your child. As parents, you know your child best. You see him/her in all areas of life (i.e., at home, school, and the store) so you are in a good position to advocate for your child. Services and the people who provide these services will change throughout your child's life, but you will remain the constant in his/her life.

In order to be an equal partner on your child's team(s), I wish to share some helpful tools for dealing with your child's health insurance, medical care, and other types of service. This notebook is designed to give you some basic information and a framework to help you gather information and coordinate supports and services for your child.

Raising children is a hard job. When you have a child with a disability of any kind, you are going to be faced with many questions and decisions. You are not alone. You will learn a lot about yourself. Reactions of anger, fear, guilt, denial and grief are all very normal. Don't ever hesitate to ask for help.

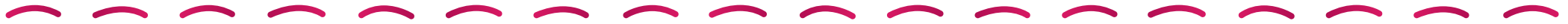
And, finally, just a note about the quilt patches and thread theme of this book. Quilts tell the stories of our lives - they offer warmth, comfort and love. May you too, find the fragments of your life and stitch together a thing of beauty.

Dana Yarbrough

BROOKE'S MOM

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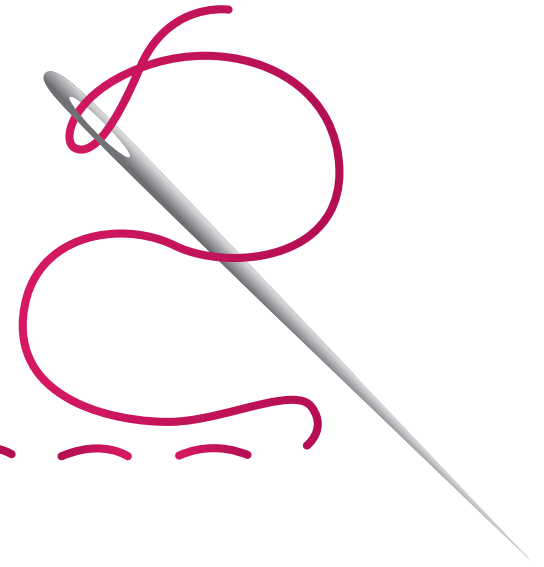


My daughter was born premature and spent much of the first 18 months of her life in the hospital. I learned very early on that I needed to study our health policy to see what they would and would not cover. And, to keep every medical bill and letter from the hospital in a binder in case I needed to file an appeal.



Chapter 1

UNDERSTANDING HEALTH INSURANCE



Understanding Health Insurance

To be an effective advocate for your family's medical needs, you will need to know the basics of health insurance coverage. This chapter will provide some general information on the different types of private and military health insurance plans as well as expected features and timelines for implementation of the Patient Protection and Affordable Care Act (ACA).

Private Health Insurance

If you have health insurance, you have either a traditional plan or some type of managed care plan. No one type of health care plan is better than the other. It really depends on your needs, preferences and budget. The first managed care plans were health maintenance organizations (HMOs). There are also preferred provider organizations (PPOs) and point of service plans (POS). Other types of plans include fee for service, which is also called an indemnity plan, and consumer-driven health plans. Below are some features that are typical of each of the basic plan types.

Managed Care Plans

CLOSED-PANEL HEALTH MAINTENANCE ORGANIZATION (HMO)

- You pay a set fee, called a premium, which is usually paid monthly.
- The HMO provides you access to services through its own network of doctors and health care facilities.
- You must go to one of the HMO doctors and you will have a co-payment for each visit, although the out of pocket fees are usually low.
- You must select a primary care physician (PCP). Your PCP is the doctor responsible for managing your health care.
- If your plan requires a referral for specialty care, your PCP must approve a referral to a specialist.

ADVANTAGES

- Coordinated approach to care and preventative care
- Lower cost
- Little paperwork (you don't have to file claims)

DISADVANTAGES

- Less choice in provider and services
- Must have a PCP
- Need a referral from PCP to see a specialist

PREFERRED PROVIDER ORGANIZATIONS (PPO)

- You choose your doctor. The plan coverage differs depending on whether the doctor is in the PPO network.
- You will have co-payments and deductibles.
- You can refer yourself to a specialist without getting approval from a primary care physician (PCP).
- If you see a doctor in the plan's network (a preferred provider), the PPO pays 80-100% of the bill.
- If you see a provider outside the plan, the PPO will pay a lower percentage.

ADVANTAGES

- Can go to any specialist in the PPO network without approval from a PCP
- Standard co-pays are \$10 to \$15
- Little paperwork (no filing of claims)

DISADVANTAGES

- Premiums may be higher. And, co-pays and deductibles are higher for using an out-of-network provider
- No PCP is required which may result in lack of care coordination
- Preventative care services may not be covered

More About Health Care Plans

POINT OF SERVICE PLANS (POS)

- Similar to PPO, but includes a primary care physician (PCP) you choose among the POS network of doctors.
- If you see a doctor in the POS network, your bills can be completely covered like an HMO.
- If you see a doctor or other provider outside the POS network, only a percentage of the bill is covered.

ADVANTAGES

- Choice in providers and services in and out of the network
- Lower cost when network provider is used
- Little paperwork when network provider used

DISADVANTAGES

- May have to submit your own claims and paperwork
- PCP required
- Higher cost when using provider outside network

CONSUMER-DRIVEN HEALTH PLANS (CDHP)

- Use personal health savings accounts (HSA) and health reimbursement arrangements (HRA) to pay routine health care expenses directly (like having a pre-funded spending account and using special debit card provided by insurer or bank).
- Use a health plan policy for catastrophic medical expenses.
- Can “rollover” unused balance for future expenses.

ADVANTAGES

- Offers tax deductions or the benefit of pre-tax dollar contributions
- Lower monthly premiums

DISADVANTAGES

- High deductibles for people with chronic conditions
- May not have ready access to information about health products and services when making critical health decisions

FEE FOR SERVICE

- You can use any doctor you like. Your provider or hospital will bill your insurance company.
- The insurance company will pay for the service covered in your policy minus any deductibles, co-pays, etc. that may apply.
- An explanation of benefits will be provided to you by the insurance company listing what they paid and the remainder that you owe to the provider.
- The insurance company might pay a claim based on what they decide is “reasonable and customary.” You will be responsible for the difference between what is charged and what the insurance company considers reasonable.

ADVANTAGES

- You select your own provider or hospital
- You are covered regardless of where you live or work
- PCP not required

DISADVANTAGES

- More paperwork (you may receive a bill each time you get health care that you have to file to get reimbursed)
- More out of pocket costs (premiums, co-pays, deductibles as high as \$1,500) and you have to pay the difference between what is paid by health plan (up to 80%) and what is owed to provider

Group vs. Individual Coverage

Most people get health insurance through their job which is a type of group insurance. An individual policy is one that you purchase on your own to cover just you or you and your family.

GROUP PLANS

Typically, there are specific times when you are allowed to enroll in a group health plan:

- **WHEN YOU ARE HIRED**
Complete simple application when you start your new job
- **DURING OPEN ENROLLMENT**
Usually during the same month each year
- **IF YOU HAVE OTHER HEALTH COVERAGE THAT ENDS**
Usually within 30 days in which to enroll

If you, or a family member, have a medical problem, the medical condition cannot make you ineligible for coverage. But, you might pay a higher premium. Check with your new employer to see if there are higher fees or a waiting period.

As a general rule, if your employer changes insurance companies, the new insurance company must insure everyone in the group. Sometimes, your deductibles and co-pays will change. When your coverage changes, study the new policy carefully. Don't assume the benefits are the same.

If your employer does not offer a group health insurance plan, check to see if any of the organizations you belong to (labor union, service club, special interest group, school) offer a group plan. Additional options are noted in the section below on the Patient Protection and Affordable Care Act.

There are two types of group plans: 1) insured, and 2) self-funded. Different laws govern the two types of plans.

- **FULLY INSURED PLANS** are structured so that the employer purchases coverage from an insurance company directly, and the insurance company assumes the financial risk to pay claims. In Virginia, these plans are regulated by the Bureau of Insurance.
- **SELF-INSURED PLANS** (or self-funded plans) are different in that the employer acts as the insurer; the employer actually pays the bills for its employees' healthcare and assumes all risks. These plans are subject to the Federal Employment Retirement Act (known as ERISA) and regulated by the U.S. Department of Labor.

INDIVIDUAL POLICIES

If you cannot get insurance through your employer or other organization, you will need to shop for your own individual plan. This is a good option if you are self-employed, but is more expensive than a group plan.

If you are buying an individual policy, the insurer will review your medical history and decide what your medical future may hold (this is called "underwriting"). Typically, the insurer will charge you higher premiums, or choose not to cover you at all if they determine your medical future is likely to involve expensive medical treatment. Additional options are noted in the section on the Patient Protection and Affordable Care Act.

In some instances, the insurer may offer you a policy with a "rider." A rider is extended coverage on a plan that might increase or decrease the scope of coverage. For example, a plan with no pharmacy benefits might include a rider for prescription coverage.

How Much Does Insurance Cost?

PREMIUMS

In any insurance plan, you or your employer will pay premiums monthly, quarterly, or yearly. If you have your own health insurance plan, you will pay the premiums yourself. If your coverage is through an employer, the premium is paid for you, although some or all of it may be deducted by your employer from your paycheck.

What an insurer chooses to charge for your premium is dependent on a number of factors. For an individual plan, people who are young, healthy, do not smoke, do not drink, do not engage in high-risk behavior, and have a clean medical history, pay the lowest premiums. They are considered low-risk for having to use medical services. People with increased health risks and women of child bearing age pay higher premiums since they are more likely to have costly medical bills.

DEDUCTIBLES

Almost all health insurance plans have deductibles. This is the amount of money you pay before your insurer will start to pay your medical bills. Your insurance deductibles apply to your total medical expenses in any one calendar or policy year. Each family member may have their own deductible, or there may be an overall family deductible.

CO-INSURANCE

Co-insurance is the percentage of the bill you pay after the deductible is met. Typically, if you have co-insurance, it is 20% of the remaining expenses.

Example of Co-Insurance:

You break your leg. You go to hospital for care. If the hospital visit was your first medical visit that year, you would have to pay a deductible. After the deductible is paid, the insurer will pay 80% of the remaining claim, you pay the remaining 20%.

$\$5000$ hospital bill - $\$250$ deductible = $\$4750$ bill

$\$4750 \times 20\%$ co-insurance = $\$950$

You pay $\$250 + \$950 = \$1200$

Your insurer pays $\$3800$

CO-PAYMENTS

A co-payment refers to a specific charge you pay every time you get a specific service (such as $\$25$ for every doctor visit, $\$20$ for every prescription filled). Co-pays are separate from deductibles and co-insurance. Your health plan may require that you pay all three.

OUT-OF-POCKET MAXIMUM

If you have a serious or chronic medical problem, you have the potential for having large medical bills. Most policies have what is called an "out-of-pocket maximum." This is the highest dollar amount a member will pay in co-payments, deductibles, and co-insurance combined, usually on a calendar year basis. After you reach that maximum level, the insurer will pay all of your medical expenses.

LIFETIME MAXIMUMS

Many policies also have lifetime maximums. This lifetime maximum is the total amount your insurer will pay out over the life of an insured person. If you have reached your maximum for out-of-pocket costs and the insurance company is paying 100% of your bills, don't assume that all of your future medical expenses will be taken care of. Lifetime maximums (even those of $\$2$ million) can accumulate rapidly if you or a family member has a serious illness.

The Insurance Policy

THE POLICY

Insurers are required to provide information that explains the care and services covered under your policy. The “full policy” (which is the contract you have with your insurer) describes all of the services, charges, exemptions and limits on services under your plan. Either you or your employer received a copy of the policy when you got coverage. Federal law requires group health insurance plans to provide you with a copy of your policy, or summary, within 90 days after you join the plan.

BENEFITS & EXCLUSIONS

Every plan has benefits and exclusions. These are the sections of the policy that will tell you about the covered services (benefits) and the specific conditions or procedures for which the plan will not provide benefits (exclusions). If you still have questions after reading the policy, call your employer’s human services coordinator or your insurance agent.

PROVIDER LIST

Managed care organizations will offer you a provider directory that includes the clinics, specialists, and doctors covered under the plan. The directory is a quick way to see if your current physician is covered under the plan.

POLICY PROVISIONS

It pays to know about your insurance.

- **WHO MAKES THE DECISIONS?** Ideally, you want to have insurance where you and your doctor make final decisions regarding your care. However, insurance plans usually have their own medical doctor who may review and make final coverage decisions.
- **ARE THERE WAITING PERIODS?** Look to see if there are any waiting periods.
- **DO YOU HAVE NOTIFICATION REQUIREMENTS?** Many policies require that you notify the plan before you have a surgical procedure (that you planned in advance) and if you are admitted somewhere for emergency treatment. Notification requirements are also known as pre-approval, prior authorization, or pre-authorization. If you don’t notify the plan as required, there is a good chance they will not pay the claim.
- **HOW MUCH DO YOU PAY?** Know how much your plan premium, co-payments, deductibles, and co-insurance rates are.
- **IS THERE A LIMIT ON MY HOSPITAL STAY?** Read your policy to find out if your policy limits the number of days you can stay in the hospital. This is especially important if you have, or develop, a serious medical problem that requires a long period of hospitalization.
- **HOW DO I APPEAL A CLAIM THAT HAS BEEN DENIED?** Read your policy to find out how your insurer handles the appeal process. Additional information can be found at the end of this chapter.

IS THE SERVICE MEDICALLY NECESSARY?

A service may be covered by your health plan but still not be considered medically necessary for your child. Determining medical necessity can be complicated, and each health plan has its own definition. Most plans use the same general principles in determining medical necessity:

- Is the service reasonable and necessary for diagnosis or treatment?
- Is the service appropriate for the child’s age, developmental status, and medical needs?
- Will the service help improve treatment, function, ability, and/or prevent deterioration?
- Is there any equally effective, less costly alternative that has not been tried and would achieve the same outcome?

Don't Be Misled

Many insurers will provide a glossy brochure that highlights the main benefits and exclusions in the policy. This is not the policy but a marketing tool designed to convince you to enroll in the plan.

COBRA

“COBRA” (Consolidated Omnibus Budget Reconciliation Act) applies to group health insurance plans sponsored by employers with 20 or more employees. Under COBRA, if you have lost your group health insurance, you are able to continue your former employer’s health coverage for you and your dependents for at least 18 months. This period may be extended up to 36 months, depending upon the “qualifying event” causing your group coverage to end. If you wish to continue your group health insurance under COBRA, you must notify your employer within 60 days of receiving notice of your COBRA eligibility.

SOME IMPORTANT THINGS TO KNOW:

- Under COBRA, you must pay the entire employer premium on a monthly basis, plus an administrative fee, to continue your health coverage under your former group plan. COBRA can be expensive, but typically costs less than the same coverage under an individual plan.
- Your COBRA coverage must be identical to the health coverage you had before.
- Under COBRA, you can be charged up to 102% of the premium to continue your health coverage under your former employer’s plan.
- If your former employer switches health plans while you are under COBRA, you may switch plans or stay with the old one.

Additional COBRA options exist for spouses and dependent children.

It is the employer’s responsibility to notify the health plan administrator within 30 days in the case of an employee’s job termination, hours of employment, eligibility for Medicare or reduced death.

It is your responsibility (or your family’s) to notify the plan administrator within 60 days in the case of divorce, legal marital separation or child’s loss of dependent status.

COBRA is complicated. Your employer’s human resources office should have a booklet that explains how COBRA works in detail. This information is also available from the Virginia Bureau of Insurance (1-800-552-7945).

Military Health Insurance

TRICARE is the Department of Defense’s worldwide health care program for active duty and retired uniformed services members and their families. TRICARE offers three plans:

- TRICARE Prime (managed care option)
- TRICARE Extra (preferred provider option)
- TRICARE Standard (fee for service option)

Active duty service members are required to enroll in TRICARE Prime. Active duty family members are encouraged, but not required to enroll in TRICARE Prime.

In the past, TRICARE ended at age 21, or age 23 for full-time college students. But in April of 2011, the Department of Defense announced its introduction of the premium-based TRICARE Young Adult Program (TYAP) which extends medical coverage to eligible military family members to the age of 26 (in accordance with the Affordable Care Act).

TRICARE Prime offers lower out-of-pocket costs than any other TRICARE option. Under TRICARE Prime, active duty members and their families do not pay annual deductibles or make co-payments for care within the TRICARE network. TRICARE Prime enrollees receive most of their care from military providers or civilian providers who belong to the TRICARE Prime network. Enrollees are assigned a care manager who manages their care and provides referrals to specialty care.

TRICARE Extra and TRICARE Standard are available for all TRICARE-eligible persons who elect or are not able to enroll in TRICARE Prime. Active duty service members are not eligible for Extra and Standard. TRICARE Extra and Standard enrollees are responsible for annual deductibles and co-insurance (cost shares). This means that, after deductibles have been met by the enrollee, a certain percentage of the cost of care will be paid by the government, with the remaining to be paid by the patient. The current cost share percentages, as of this printing, are shown on the next page.

More About Military Health Insurance

ACTIVE DUTY FAMILY MEMBERS

TRICARE PRIME

- Annual Deductible: None
- Annual Enrollment Fee: None
- Civilian Outpatient Visit: \$0
- Civilian Inpatient Admission: \$0

TRICARE EXTRA

- Annual Deductible:
E-5 and above - \$150 per individual or \$300 family
E-4 and below - \$50 per individual or \$100 family
- Annual Enrollment Fee: None
- Civilian Outpatient Visit: \$16.85/day or \$25 per admission (whichever is greater)
- Civilian Inpatient Admission: \$16.85/day or \$25 per admission (whichever is greater)

TRICARE STANDARD

- Annual Deductible:
E-5 and above - \$150 per individual or \$300 per family
E-4 and below - \$50 per individual or \$100 per family
- Annual Enrollment Fee: None
- Civilian Outpatient Visit: \$16.85 per day or \$25 per admission (whichever is greater)
- Civilian Inpatient Admission: \$16.85 per day or \$25 per admission (whichever is greater)

RETIREES, THEIR FAMILY MEMBERS & OTHERS

TRICARE PRIME

- Annual Deductible: None
- Annual Enrollment Fee:
\$230 per individual or \$460 per family
- Civilian Outpatient Visit: \$12
- Emergency Care: \$30
- Civilian Inpatient Admission:
\$11 per day (minimum) or \$25 for admission

TRICARE EXTRA

- Annual Deductible:
\$150 per individual or \$300 per family
- Annual Enrollment Fee: None
- Civilian Outpatient Visit: 20% of negotiated fee
- Emergency Care: 20% of negotiated fee
- Civilian Inpatient Admission:
Lesser of \$250 per day or 25% of negotiated charges plus 20% of negotiated professional fees

TRICARE STANDARD

- Annual Deductible:
\$150 per individual or \$300 per family
- Annual Enrollment Fee: None
- Civilian Outpatient Visit:
25% of allowable charges for covered service
- Emergency Care:
25% of allowable charges for covered service
- Civilian Inpatient Admission:
Lesser of \$535 per day or 25% of billed charges plus 25% of allowable professional fees

EXTENDED CARE HEALTH OPTION

The Extended Care Health Option (ECHO) is a program that is available only to families of active duty service members enrolled in the Exceptional Family Member Program whose family member(s) has substantial needs. ECHO supplements limited benefits, or benefits not available through TRICARE and includes, but is not limited to, items such as special education, durable equipment, training to use assistive technology devices, rehabilitative care, and respite care.

Conditions that are eligible for ECHO include:

- Moderate to Severe Intellectual Disabilities
- Serious Physical Disability
- Extraordinary Physical or Psychological Condition of such Complexity that the Beneficiary is Homebound

More About Military Health Insurance

EXCEPTIONAL FAMILY MEMBER PROGRAM

The Exceptional Family Member Program (EFMP) is a mandatory enrollment program that works with military and civilian agencies to provide comprehensive and coordinated community support, housing, educational, medical and personnel services to active duty personnel who have children with disabilities.

The EFMP specialist may look different in each branch of the military, but their role is similar – to assist with enrollment, provide resources and referrals, and ensure access to vital medical, educational and community services.

Health Insurance Portability & Accountability Act

The U.S. Department of Health and Human Services' Office for Civil Rights has the responsibility for enforcing the Health Insurance Portability and Accountability Act (HIPAA) of 1996. A major goal of HIPAA's privacy rule is to assure that your health information is properly protected while allowing the flow of health information needed to provide you with high quality health care.

Protected health information includes demographic data that relates to your past, present or future physical or mental health or condition; payments for providing your health care; and anything that would identify you (i.e., name, address, social security number).

Patient Protection & Affordable Care Act

In March 2010, President Obama signed comprehensive health reform, the Patient Protection and Affordable Care Act (ACA), into law. The law expands health care coverage, controls health care costs, and improves the health care delivery system. Because implementation is just beginning at the time of the printing of this book, the graphic on the next page is an attempt to provide a snapshot of major ACA provisions and timelines.

The things that are most important to know about ACA as it relates to children and youth with special health care needs and disabilities are:

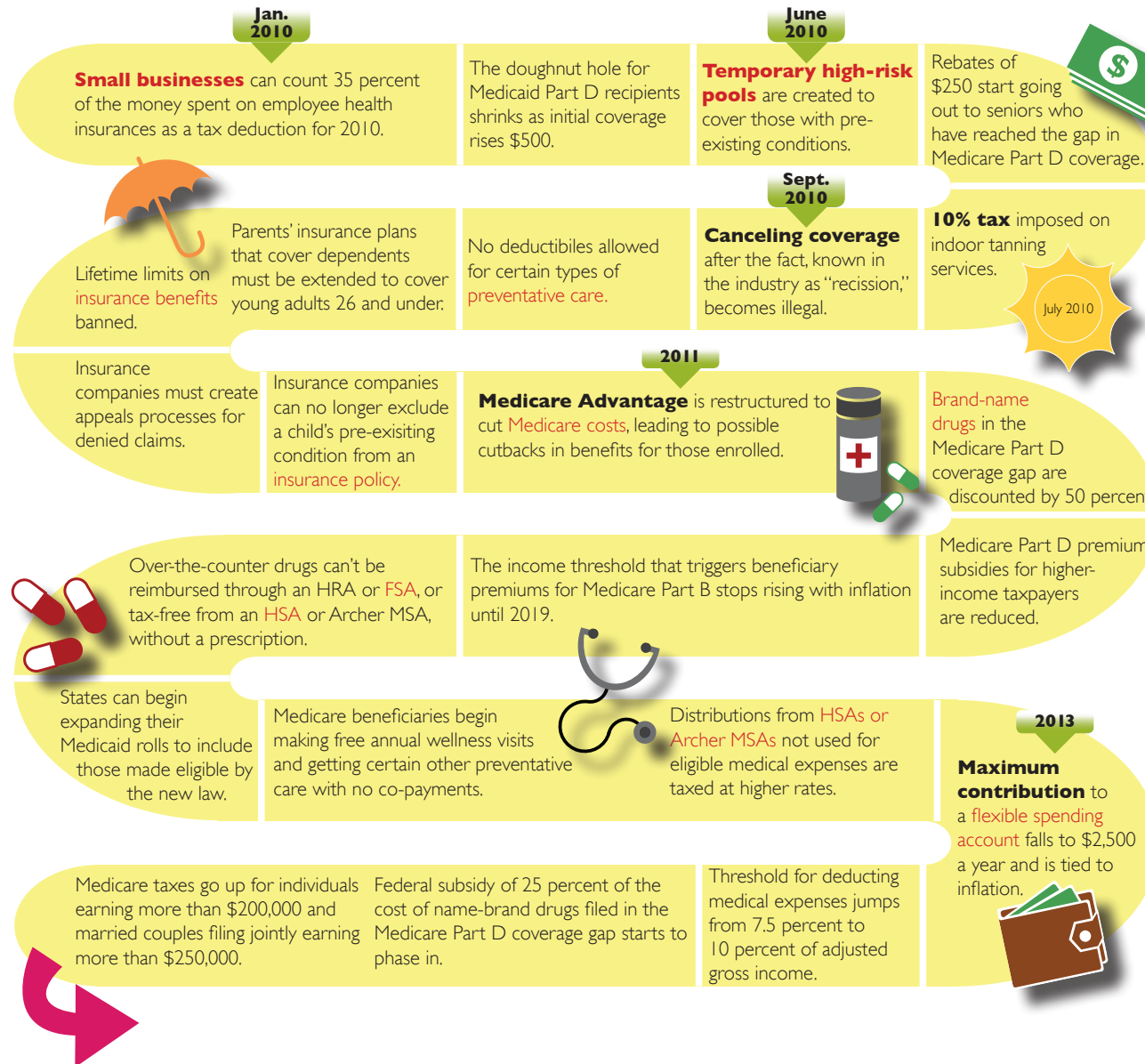
- Insurance Plans Cannot Deny Coverage Based on Pre-Existing Conditions (A Health Care Need that was Present Before a Person Joined the Health Care Plan, like Cerebral Palsy)
- Exchange Plan Options will be Offered for Uninsured Children with Special Health Care Needs/Disabilities who were Previously Denied Coverage Based on Pre-Existing Conditions
- No Annual or Lifetime Benefit Caps
- Coverage of Young Adults up to Age 26 on their Parent's Policy even if the Young Adult No Longer Lives at Home
- Requirement for Preventative Care at no cost and Prohibition of Charging Co-Pays, Deductibles and Co-Insurance for Preventative Care

COMMUNITY LIVING ASSISTANCE SERVICES & SUPPORTS PROVISIONS

One provision of the ACA is a federally administered voluntary long-term care insurance program called the Community Living Assistance Services & Supports (CLASS) program that is intended to provide people with disabilities tools that allow them to maintain their personal and financial independence and live in the community. Once established, employed individuals aged 18 and older could voluntarily enroll in the CLASS program. Benefits would include a cash benefit that can be used to purchase things like home modifications, assistive technology, respite care, and transportation; advocacy services; and assistance with accessing and coordinating long term care services.

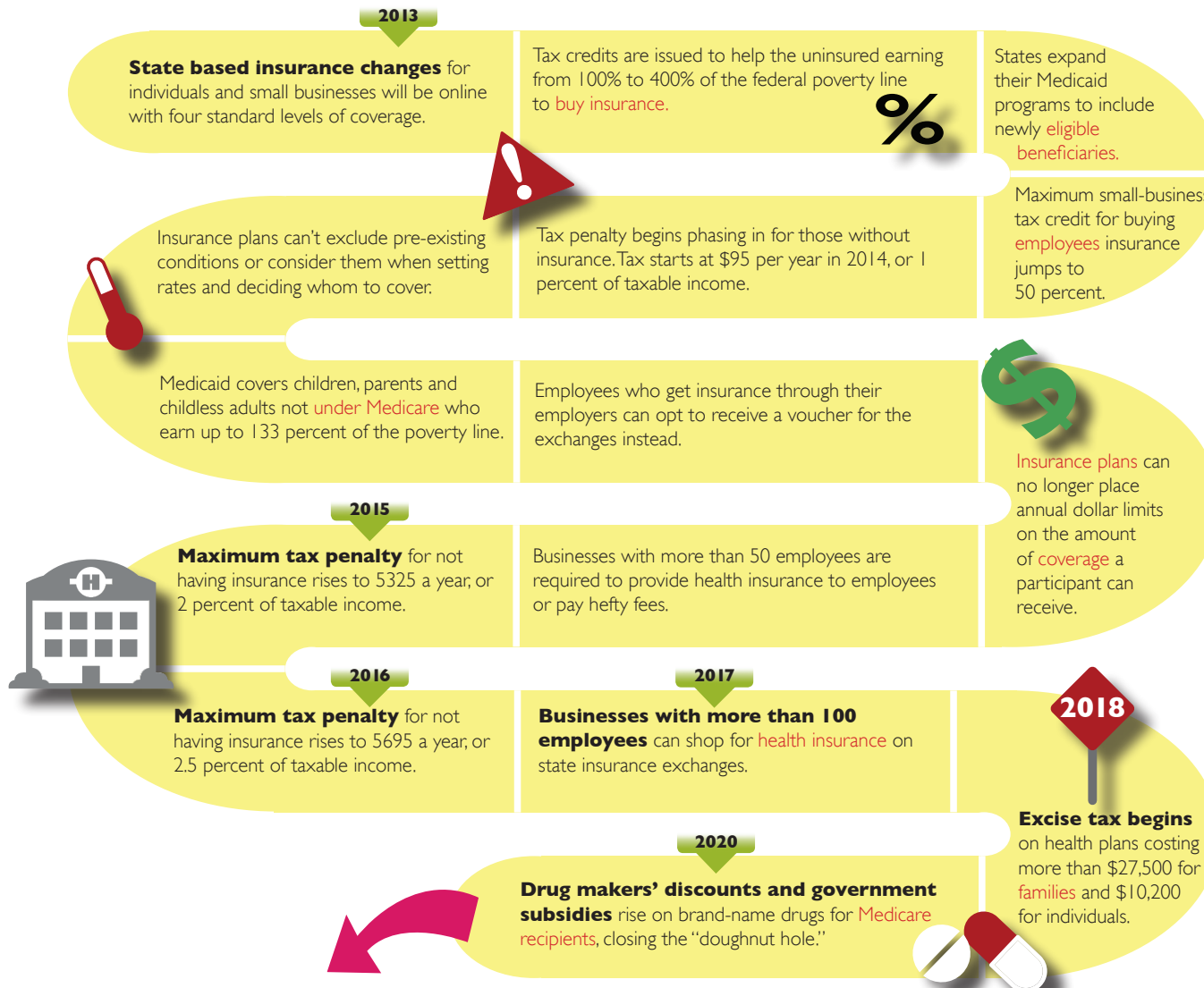
HEALTH CARE REFORM TIMELINE

This timeline will you keep track of when the law's key changes will occur



HEALTH CARE REFORM TIMELINE

(Continued)



From the Administration on Developmental Disabilities

How To File Insurance Appeals

You can avoid many of the most common insurance problems by making sure you understand your health plan. But even the most sophisticated consumer can run up against a bewildering denial of service or payment for services.

PRIVATE HEALTH INSURANCE

INFORMAL RESOLUTION

When you have a dispute with your insurance company, first try to resolve it informally.

- Try to approach your insurer in an open and friendly manner
- Threats of legal action may cause the insurer to react defensively
- Investigate the facts of your case – denials should be made based on provisions written in your policy.
- Call a customer services representative at your insurer's office and ask why the claim was denied. Ask for it in writing. Check the reason against the provisions in your policy. If the denial is not based on written policy provisions, you have a good chance of having it reversed.

Keep a record of when you called, with whom you spoke, and what was said. This paper trail may be important if your complaint is not resolved quickly and to your satisfaction. There are forms to assist you in Chapter 10.

INTERNAL GRIEVANCE

If your initial contact with the insurer did not resolve the issue, you will need to get their attention by writing a letter. Read your policy for specific instructions on how to file your complaint. Some sample letters are included in Chapter 10 of this notebook.

- Send a letter by registered mail asking for an explanation of the medical reasons your claim was denied, the names of those responsible for making the decision to deny the claim, whether these individuals have medical expertise relevant to your problem, and the specific section of your insurance policy they are relying on to deny the claim
- Include copies of letters from your doctors
- If you have a second opinion, include a copy

Typically, the insurer has five business days to acknowledge receipt of your written grievance. Usually, a plan's appeal board (made up of physicians and administrators) reviews your grievance and makes a decision within 30 days (self-funded plans have 60 days). All insurance plans are required to provide you with a written reason why a service is denied or not covered.

Do not be surprised if your first grievance is denied. Don't give up! An initial denial does not mean you've come to a dead-end. Be persistent. Do not accept "no" if you feel you are right.

File a complaint with the Virginia Bureau of Insurance if you do not receive a written explanation from your insurer listing the specific reason for the denial (www.state.va.us/scc/division/boi). If an appeal of benefits is denied by the health plan you have through your employer, you should talk to your human resources coordinator about contacting the insurer on your behalf.

More About How To File Insurance Appeals

MORE ABOUT PRIVATE HEALTH INSURANCE

INDEPENDENT REVIEW

If you have exhausted your insurer's grievance procedure, you might want to pursue an independent review. In this process, someone from outside the insurance company reviews the merits of the grievance. Typically you have up to four months to request an independent review after you have followed all the other steps. The independent review organization has 30 business days to make its decision. Once this decision is made, it is binding on both you and the insurer. This means that you cannot take the insurance company to court if you disagree with the decision.

It is important to note, that if you are covered through Medicaid or another federal insurance plan, or if you are covered through your employer's self-funded insurance plan, you cannot request an independent review.

ARBITRATION

Sometimes, if your appeal is denied, your insurance company will require you to go through arbitration before going through an independent review or the courts. For plans that do not have arbitration, you may choose to bypass any further appeals altogether and go directly to court. If you choose arbitration, consider hiring an attorney to present your case.

COURT ACTION

Most employer sponsored health plans are protected from certain lawsuits challenging claim denials. There are some cases when going to court may be helpful. Contacting an attorney should be your last step. Attorneys can be expensive. Some attorneys will take a case on a contingency basis where you only pay if the attorney wins your case. Many attorneys won't take this type of case unless the claim is financially rewarding.

More About How To File Insurance Appeals

MILITARY HEALTH INSURANCE

Beneficiaries who disagree with certain decisions related to their benefits made by TRICARE Management Activity or by a TRICARE contractor have the right to appeal that decision. The appeals process varies, depending on whether the denial of benefits involves a medical necessity determination, provider authorization, etc.

Any TRICARE beneficiary or parent/guardian of a beneficiary who is under 18 years of age can appeal one of the following decisions:

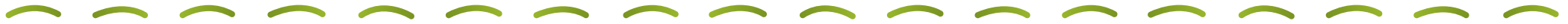
- A decision denying TRICARE payment for services or supplies received
- A decision denying preauthorization for requested services or supplies
- A decision terminating TRICARE payment for continuation of services or supplies that were previously authorized

Decisions related to the eligibility as a TRICARE beneficiary cannot be appealed as eligibility is determined by enrollment in the Defense Enrollment and Eligibility Reporting System. Beneficiaries must address decisions regarding eligibility through their service branch.

All beneficiaries must:

- Meet all required deadlines (typically within 90 days of the date on the explanation of benefits or decision)
- Send appeals in writing with signatures
- Include copies of all supporting documents in the appeal
- Keep copies of everything

Once an appeal letter has been submitted in writing within established timelines, the TRICARE contractor will review the case and issue a reconsideration decision. If you disagree with the reconsideration decision, the next level of appeal is the national quality monitoring contractor. Again, your appeal must be submitted in writing within 90 days of the date of the reconsideration decision, and the national quality monitoring contractor will review the case and issue a second reconsideration decision. If the amount of the dispute is less than \$300, the reconsideration decision by the national quality monitoring contractor is final. If you still disagree with the decision, and if the disputed services are more than \$300, you can request that TRICARE Management Activity schedule an independent hearing.



As a parent and caregiver for my grandson, I am so very thankful that he has the ID Waiver and the services he receives from it. He benefits daily from the Waiver services that allow him to remain in the community with necessary supports and lead a more normal life around people who love and care about him.



Chapter 2

THE BASICS OF STATE SPONSORED INSURANCE PROGRAMS & WAIVERS



The Basics of State Sponsored Insurance Programs & Waivers

Medicaid is a joint program between federal and state governments. Medicaid was set up by Congress to provide health care primarily to people who have low income and who are elderly, disabled, or pregnant; and to low-income families with children. Children with disabilities enrolled on a Medicaid Waiver can also get Medicaid insurance.

Medicaid covers certain services for all Medicaid eligible people who need those services. The federal Medicaid center publishes a list of mandatory services that all states must provide. There is also a second list published that lists optional services states can choose to provide. States can control the cost of Medicaid by limiting the number of services it chooses to provide or by making eligibility requirements more strict.

Medically Indigent Medicaid (F.A.M.I.S. Plus) & Family Access to Medical Insurance Security (F.A.M.I.S.)

Virginia has two state sponsored health insurance programs for children. FAMIS is Virginia's state children's health insurance program. FAMIS Plus is Virginia's name for children's Medicaid. Both programs are operated by the Virginia Department of Medical Assistance Services (www.dmas.virginia.gov).

WHO QUALIFIES?

Your child may be eligible for FAMIS or FAMIS Plus (Medicaid) if they:

- Live in Virginia
- Are under the age of 19
- Are U.S. citizens or certain aliens who are legal residents (a parent's citizenship is not considered)
- Live in families that meet income guidelines

For FAMIS only, children:

- Must be uninsured at the time of application
- Cannot have had health insurance in the past 4 months (There are some exceptions that apply to this rule)
- Cannot be eligible for the Virginia state employee health plan

HOW MUCH DOES IT COST?

There are no enrollment costs or monthly premiums to pay for FAMIS or FAMIS Plus. There are no co-payments for any medical services under FAMIS Plus if you are under the age of 21. It is free. With FAMIS, there is a small charge (co-payment) when your child receives certain services. It is usually \$2 to \$5.

Important:

Enrollment in FAMIS or FAMIS Plus will have no effect on your immigration status. Information on your application for insurance is not shared with immigration authorities.

More About F.A.M.I.S. & F.A.M.I.S. Plus

Famis Income Limits

Effective January 11, 2011. Income limits are adjusted annually.

FAMILY SIZE	GROSS INCOME LIMIT
1 Family Member	\$21,780 per year or \$1,815 per month
2 Family Members	\$29,420 per year or \$2,452 per month
3 Family Members	\$37,060 per year or \$3,089 per month
4 Family Members	\$44,700 per year or \$3,725 per month
5 Family Members	\$52,340 per year or \$4,362 per month
6 Family Members	\$59,980 per year or \$4,999 per month
7 Family Members	\$67,620 per year or \$5,635 per month
8 Family Members	\$75,260 per year or \$6,272 per month
Each Additional Family Member	\$7,640 per year or \$637 per month

Qualifying for FAMIS or FAMIS Plus also depends upon household income and family size. Children are eligible for FAMIS Plus with family income up to 133% of the Federal Poverty Level. The family income can be higher (up to 200% of the Federal Poverty Level) for FAMIS.

When calculating family size for FAMIS and FAMIS Plus, parents and children up to age 21 in the home are counted. Grandparents, friends and relatives are not counted. Some income is not counted. For example, student income is not counted. Stepparent's income is not counted for FAMIS Plus, but is counted for FAMIS.

There are deductions to income that can be taken (for working parents, child support, child care, etc.) If your family is close to the income limits, these deductions can make a difference, so apply to find out if your children qualify.

WHAT ARE THE INCOME REQUIREMENTS?

The chart to the left gives you an idea of how much you can make and still qualify for FAMIS. The income numbers used in the chart are current as of January 2011. Maximum income guidelines increase each year. You can contact your local Department of Social Services (DSS) for current income guidelines. You can also find income numbers for FAMIS and other information about FAMIS by calling 1-866-87-FAMIS or at www.famis.org. Information is available on this website in English and Spanish and some information is available in other languages.

HOW DO I APPLY?

It is easy to apply for FAMIS and FAMIS Plus. The same application is used for both programs. Eligibility for these programs is determined by local Departments of Social Services (DSS) or by the FAMIS Central Processing Unit (CPU). You can apply by phone, fax to 1-888-221-9402 (fax), online, or mail your completed application to your local DSS or to FAMIS, P.O. Box 1820, Richmond, Virginia 23218-18209.

To get started, call the CPU toll free at 1-866-87FAMIS Monday through Friday (8 am to 7 pm) or Saturday (9 am to 12 noon). Interpreters are available at this number. Or visit your local DSS to apply.

WHO CAN APPLY?

Parents and legal guardians can apply on behalf of the child. If you are taking care of a relative's child, you can apply for that child. If you have written permission from the child's parents, any adult can apply on behalf of the child.

When you apply, you will need to show proof of income. The application requirements are:

- Child's Social Security Number, or a copy of application for a Social Security card
- If you are not the parent & not related to the child by blood or marriage, proof of legal guardianship (or written permission from a parent is required)
- Proof of the child's immigration status, if applicable
- Paycheck stubs from the previous month's pay stub (or a letter from your employer that verifies wages)
- If parent is self-employed, copy of income tax return
- Copies of monthly benefit checks or Social Security statement, if applicable
- Verification of child support, if applicable

More About F.A.M.I.S. & F.A.M.I.S. Plus

WHAT HAPPENS ONCE MY CHILD IS ENROLLED?

When an application is determined to meet eligibility requirements (a 45 day timeline from the time a completed application is received), the child/children are enrolled. Once enrolled, FAMIS cases are maintained by the CPU and FAMIS Plus cases are maintained by the local DSS.

All children start out in a fee-for-service plan and will receive a DMAS identification card. Some children (i.e., those in foster care or already receiving health insurance through a comprehensive group or individual health insurance plan) will remain in fee-for-service regardless of where they live. Most children, however, will be assigned within a month to a managed care plan (if there is one available in their region) or to a Primary Case Manager plan. When there is more than one managed care option available in the region, the family will be given a choice of plans. If the family does not choose, they will be assigned to a plan. Once enrolled in a managed care plan, the child will also receive a plan identification card. Both cards (DMAS and health plan) must be kept and presented to the provider (i.e., doctor, hospital) when services are received.

Every 12 months the child/family must be re-determined for continued eligibility for FAMIS or FAMIS Plus. That is, there is an annual renewal required (based upon the child's enrollment date) in order for the insurance coverage to continue. If your child's application for FAMIS or FAMIS Plus is denied, or benefits are terminated, you should appeal the decision. More information on filing appeals can be found at the end of this chapter.

For FAMIS children, if the application is approved, the insurance coverage is effective the first day of the month the completed application was received. FAMIS has no premiums and there are no co-pays for preventative care. But, there are co-pays for other medical services (\$2 - \$3); and for hospital admissions (\$15 - \$25). If a service is billed above the coverage limit, the family may receive a bill.

For FAMIS Plus children, once the child is determined to be eligible, health care bills that are as much as 3 months old can be submitted for payment consideration. FAMIS Plus is free; there are no premiums or co-pays if under the age of 21.

WHAT SERVICES ARE COVERED?

The following summarizes covered services under FAMIS and FAMIS Plus:

FAMIS Plus

- Doctor/clinic visits
- EPSDT Early & Periodic Screening, Diagnosis & Treatment (See the next page for more information)
- Hospitalization
- Prescription drugs

- Dental care
- Orthodontics (necessary)
- Vision care
- Mental health (via CSB)
- School-based services
- Non-emergency transportation

FAMIS (IN A MANAGED CARE AREA)

- Doctor/clinic visits
- Well-child checkups
- Hospitalizations
- Prescription drugs
- Dental care (capped)
- Orthodontics (capped)
- Vision care (capped)
- Mental health (limited)
- School-based services

Please note that in some areas of Virginia where there are no managed care organizations, FAMIS benefits differ from above.

For more information, call 1-866-87FAMIS or go to the Virginia Department of Medical Assistance Services website at www.dmas.virginia.gov.

Early & Periodic Screening, Diagnosis & Treatment

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is a comprehensive package of benefits available to children and youth under age 21 enrolled in Medicaid. As mentioned earlier, when we talk about Medicaid for children under 19 in Virginia, we are talking about FAMIS Plus. Under EPSDT, FAMIS Plus children and youth are entitled to regular physical exams, and full physical and mental health care to treat any conditions found as a result of the examinations. Your child does not have to be sick in order to be screened.

These screenings must include examinations 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 (i.e. immunizations)

There are three types of screenings provided. The first is called an initial screen. This is a physical exam that must be provided when a child enters the FAMIS Plus program. The second type of screen is called a periodic screen (child "well" visits) which should occur at regular intervals (for example, a baby should get six hearing and vision screenings in the first 12 months). The third type of screen is called an interperiodic screen. This is a physical exam that can happen any time outside of a regular scheduled visit if a child shows signs of illness or a change in his/her condition.

Once a child is seen by his/her doctor and a screen reveals a problem, a diagnosis is made and appropriate treatment can be provided. 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." This means that states cannot refuse to provide services based on whether or not they will cure a condition. For instance, a child with an intellectual disability can receive speech therapy under EPSDT to keep from losing any current function, if the therapy is determined to be medically necessary to maintain the child in their current condition.

For a treatment to be covered under EPSDT, it must:

- Be medically necessary
- Fit within a recognized Medicaid service category; and
- Be prescribed and provided by a Medicaid provider

The Medicaid Act defines the comprehensive package of EPSDT services. Covered services under EPSDT include all mandatory and optional services that the states are allowed to cover under Medicaid, whether or not such services are covered for adults. Some of the EPSDT covered services include:

- | | | |
|---|---|--|
| <ul style="list-style-type: none">• Inpatient Hospital Services• Outpatient Hospital Services• Laboratory & X-ray Services• EPSDT Screening Services• Physician Services• Home Health Care Services• Private Duty Nursing Services• Personal Care Services• Dental Services | <ul style="list-style-type: none">• Physical, Occupational & Speech Therapy• Prescribed Drugs• Prosthetic Devices• Eyeglasses• Inpatient Psychiatric Hospital Services• Hospice Care• Case Management Services• Respiratory Care Services• Other Needed Services, Treatment & Measures For Physical & Mental Illnesses & Conditions | <ul style="list-style-type: none">• Assistive Technology• Durable Medical Equipment• Supported Living Arrangement Services (Personal Assistance, Assistive Technology, etc.) |
|---|---|--|

Important:

Some EPSDT services must be pre-authorized by DMAS in order for the cost to be covered.

The Health Insurance Premium Payment (H.I.P.P.) & H.I.P.P. for Kids Programs

The Health Insurance Premium Payment (HIPP) and HIPP For Kids Programs are Medicaid premium assistance programs, administered by the Department of Medical Assistance Services (DMAS) for Medicaid enrollees. These programs may reimburse part or all of your monthly cost of the employer sponsored group health insurance premium. Members of your family eligible for FAMIS Plus will still be covered by FAMIS Plus, but as a secondary insurance plan. Your group insurance plan will be the primary plan. That is, FAMIS Plus will pay for some services not covered by the employer's group health insurance.

Eligibility for the HIPP program is determined through a cost-effectiveness evaluation of your health insurance plan, services, and premium. This evaluation looks at your current health insurance plan and performs a comparison of the average Medicaid cost for your Medicaid eligible family member to the cost of your health insurance premium. If it is determined to be cost-effective, DMAS will reimburse part or all of your health insurance premium.

Requirements for the HIPP For Kids program is that the Medicaid eligible member is under the age of 19, is eligible for or enrolled in "qualified employer-sponsored coverage," and the family member's employer must contribute at least 40% towards the cost of the health insurance premium.

If you are determined eligible for one of these programs, on a monthly basis, DMAS will reimburse you for a portion of, or the entire amount of, the insurance premiums that are deducted from your paycheck. Your premiums will be reimbursed by DMAS as long as the family member remains FAMIS Plus eligible and continues to qualify for the HIPP or HIPP For Kids program.

Under the HIPP and HIPP For Kids programs, any changes in employment, insurance coverage, or household must be reported to DMAS immediately. Every month you will be required to send DMAS a copy of your most recent paycheck showing the insurance premium deductible. If you have questions, call the DMAS HIPP toll free line at 1-800-432-5924.

F.A.M.I.S. Select Premium Program

Virginia also has a premium assistance program for working families who may not be able to afford the premiums of private or employer-based health insurance. This program, FAMIS Select, helps families pay for private or employer-sponsored health insurance. It offers families with children enrolled in FAMIS more health care coverage options. The FAMIS Select program allows families to choose between covering their children through FAMIS or through a private or employer-sponsored health plan. Families enrolled in FAMIS Select get up to \$100 per enrolled child per month to help pay the family health insurance premium. Although the total monthly FAMIS Select payment cannot exceed the total amount of the family premium, this payment may help parents afford private or employer-based coverage for the whole family for the first time.

Income guidelines for FAMIS Select are the same as for FAMIS. That is, FAMIS Select is available to eligible Virginia residents with an income between 133% and 200% of the Federal Poverty Level (see FAMIS Income chart earlier in this chapter). Through FAMIS Select, the family has a choice to enroll their FAMIS eligible child in their employer's insurance plan rather than choose the FAMIS plan. This could benefit the family by allowing all members of a family to have the same health coverage, and may also increase access to providers who accept insurance through private plans.

For more information about the FAMIS Select Premium program, call 1-888-802-KIDS or visit the FAMIS website at www.FAMIS.org.

Home & Community-Based Medicaid Waivers

Home and community-based Waivers were established by Congress to slow the growth of Medicaid spending for nursing home care and other institutional costs. The Waiver program also addresses the concerns of people with disabilities who object to being institutionalized as the only means to get support for their needs.

If your child is disabled and/or has a severe chronic illness and requires long-term care, he may be eligible for a Medicaid Waiver. Eligibility is determined first by whether the child would require placement in a nursing home or hospital, or in an intermediate care facility for people with an intellectual disability. A Medicaid Waiver essentially says that your child is eligible for such placement, but you waive his/her right to live in an institutional setting and choose to have him/her live at home or in your community.

In Virginia there are 7 Medicaid Waivers, each with its own eligibility criteria and specific population served. These are:

- Alzheimer's Assisted Living (AAL) Waiver
- Day Support Waiver
- Elderly or Disabled with Consumer Direction (EDCD) Waiver
- HIV/AIDS Waiver
- Individual & Family Developmental Disabilities Support (DD) Waiver
- Intellectual Disability (ID) Waiver
- Technology Assisted (Tech) Waiver

All Waivers are not created equal. Some Waivers have a higher cost of living allowance than others. Services vary between Waivers. Some services have limits, some do not. And some Waivers have waiting lists.

Once your child is enrolled in a Waiver, you will receive a Medicaid card for your child to receive state plan Medicaid (FAMIS Plus) services. If you already have other insurance, Medicaid (FAMIS Plus) becomes your secondary insurance plan.

Current Waivers require a great deal of choice and control by the individual. You choose the case management/support coordination agency, the service agencies, and the services needed. You control when, where, and how you receive services. The following pages list the eligibility criteria and services currently available under Virginia's Medicaid Waivers for which most children with special health care needs and disabilities are eligible.

For more information, contact the DMAS at www.dmas.virginia.gov or 1-804-786-1465, the Medicaid Waiver Technical Assistance Center at 1-866-323-1088, or a Medicaid Waiver Mentor at VaWaivers@yahoo.com.

Current Waivers

INDIVIDUAL & FAMILY DEVELOPMENTAL DISABILITIES WAIVER (DD)

WHO IT SERVES:

Individuals who are over 6 years old, who have a developmental disability and do not have a diagnosis of an intellectual disability.

FINANCIAL ELIGIBILITY:

Local Department of Social Services determines income eligibility (45 day timeline). Monthly income limits of 300% of Federal Poverty Level and up to \$2,000 of assets (bonds, savings, etc.). Parent's income not considered for children.

HOW SCREENED:

Virginia Department of Health Child Development Clinics and certain local Health Districts conduct the screenings using a Level of Functioning survey.

SERVICES INCLUDED:

- Adult Companion (Consumer-Directed & Agency)
- Assistive Technology
- Crisis Stabilization
- Day Support & Prevocational Services
- Environmental Modifications
- Family/Caregiver Training
- In-Home Residential, Personal Assistance (Consumer-Directed & Agency)
- Personal Emergency Response System (PERS)
- Respite Care
- Skilled Nursing
- Supported Employment
- Therapeutic Consultation.

ELDERLY OR DISABLED WITH CONSUMER DIRECTION WAIVER (EDCD)

WHO IT SERVES:

Individuals who are over age 65 or individuals who are disabled and meet level of care requirements for admission to a nursing facility.

FINANCIAL ELIGIBILITY:

Local Department of Social Services determines income eligibility (45 day timeline). Monthly income limits of 300% of Federal Poverty Level and up to \$2,000 of assets (bonds, savings, etc.). Parent's income and assets are not considered for children.

HOW SCREENED:

A Local Pre-Admission Screening Team conducts the screening, unless the individual is in a hospital (then hospital discharge planner completes screening). The Uniform Assessment Instrument is used to determine eligibility.

SERVICES INCLUDED:

- Adult Day Health Care
- Personal Care (Agency & Consumer-Directed)
- Personal Emergency Response System (PERS)
- Respite (Agency, Consumer-Directed & Skilled)

For Individuals Transitioning from an Institutional Setting:

Money Follows the Person (MFP) transition coordination, transition services, assistive technology, and environmental modifications are available for all of the Waivers except the Day Support Waiver.

Additional Current Waivers

INTELLECTUAL DISABILITY WAIVER (ID)

WHO IT SERVES:

Individuals up to age 6 who have a developmental delay and persons who are over 6 years old who have a diagnosis of an intellectual disability.

FINANCIAL ELIGIBILITY:

Local Department of Social Services determines income eligibility (45 day timeline). Monthly income limits of 300% of Federal Poverty Level and up to \$2,000 of assets (bonds, savings, etc.). Parent's income not considered for children.

HOW SCREENED:

The local Community Services Board conducts the screening using a Level of Functioning survey.

SERVICES INCLUDED:

- Adult Companion (Consumer-Directed & Agency)
- Assistive Technology
- Crisis Stabilization
- Day Support
- Prevocational & Environmental Modifications
- Personal Assistance
- Personal Emergency Response System
- Residential Support (Group Home Or Individual's Home)
- Respite Care (Consumer-Directed & Agency)
- Skilled Nursing
- Supported Employment
- Therapeutic Consultation

TECHNOLOGY ASSISTED WAIVER

WHO IT SERVES:

Individuals who are dependent upon technological support and require ongoing, substantial nursing care.

FINANCIAL ELIGIBILITY:

Local Department of Social Services determines income eligibility (45 day timeline). Monthly income limits of 300% of Federal Poverty Level and up to \$2,000 of assets (bonds, savings, etc.). Parents income not considered for children.

HOW SCREENED:

A Local Pre-Admission Screening Team conducts the screening, unless the individual is in a hospital (then hospital discharge planner completes screening). The Uniform Assessment Instrument is used to determine eligibility.

SERVICES INCLUDED:

- Assistive Technology
- Environmental Modifications
- Personal Care (Only for Over Age 21)
- Private Duty Nursing & Respite Care (Skilled)

DAY SUPPORT WAIVER

WHO IT SERVES:

Individuals up to age 6 who have a developmental delay and persons who are over 6 years old who have a diagnosis of an intellectual disability on the ID Waiver waiting list.

FINANCIAL ELIGIBILITY:

Local Department of Social Services determines income eligibility (45 day timeline). Monthly income limits of 300% of Federal Poverty Level and up to \$2,000 of assets (bonds, savings, etc.). Parent's income not considered for children.

HOW SCREENED:

The local Community Services Board conducts the screening using a Level of Functioning survey.

SERVICES INCLUDED:

- Day Support
- Prevocational & Supported Employment Services

How to File Appeals

FAMIS PLUS & FAMIS

APPLICATION DENIED

If your application is denied or insurance benefits terminated, contact your local Department of Social Services immediately as there are timelines.

You must request your appeal in writing within 30 days to the Virginia Department of Medical Assistance Services. Your local Department of Social Services worker can help you fill out the forms for the appeal. If you need an advocate or lawyer to help you, you can call Legal Aid at 1-800-578-8111.

Once you file an appeal, you will have a hearing before a Hearing Officer. Before this hearing, your local Department of Social Services may contact you to discuss your situation in an informal conference. Do not drop your appeal. Within 90 days of submitting your appeal, the Hearing Officer must make a decision. If the Hearing Officer denies your application or termination of insurance benefits, further appeal is available to a state court.

It is important to note that if your child's insurance benefits are terminated, and you request an appeal within 10 days of receiving your termination notice, you can continue to receive benefits throughout this appeal process if you clearly state that you want your benefits to continue. But, if you lose your appeal, you may be asked to repay any benefits received during the appeal process.

SERVICES DENIED

If you are receiving benefits and a claim is denied, you have 30 days to request an appeal. As mentioned above, you may want to begin by informally contacting the Medicaid office by phone and in writing to try to resolve the problem. But don't take too much time. Remember, you only have 30 days.

If the problem still exists after your informal attempts to resolve the problem, submit a request for an appeal. Requests must be sent in writing to the Virginia Department of Medical Assistance Services. Within 90 days of your request, the hearing officers should issue a decision. If you do not agree with the decision, you may appeal through the courts.

MEDICAID WAIVERS

You have 30 days to request an appeal for these situations:

- Services are denied, reduced, or terminated;
- There is a delay in your request for services; or
- There are no providers for services that you are approved to receive.

Hearing requests should be submitted in writing to the Virginia Department of Medical Assistance Services. Within 90 days of your request, the hearing officers should issue a decision. If you do not agree with the decision, you may appeal through the courts.



“ I have found that applying for SSI was time-consuming, but well worth the effort. Since my daughter might not be able to earn enough money to support herself, SSI assistance is critical to help with her expenses. ”

Chapter 3

SUPPLEMENTAL SECURITY INCOME



Supplemental Security Income

Supplemental Security Income (SSI), from the Social Security Administration, pays monthly benefits to people who are age 65+, blind, or have a disability and who meet income eligibility requirements. SSI is not just for adults. Monthly benefits can go to children with disabilities, too. As its name implies, SSI supplements a person's income up to a certain level. The level varies from one state to another and can go up every year based on cost-of-living increases. For example, in 2011 the maximum SSI payment for a person in Virginia is \$674 per month. For the current guidelines or more information about applying for SSI, call 1-800-772-1213 or visit www.ssa.gov.

Whether a person can receive SSI assistance depends on his income level and other assets (what the person owns). Income is the money a person has coming in, such as wages, Social Security benefits, child support, and pensions. Income also includes non-cash items a person might receive such as food stamps, clothing, or shelter. If the person is married, the Social Security Administration also takes into account the income of the spouse and the things he or she owns. If the person is under 18, the Social Security Administration considers the income and assets of their parents.

The amount of income a person can have each month and still get SSI depends partly on where the person lives. The things a person owns that are considered include items such as real estate, bank accounts, cash, stocks and bonds, and Christmas club accounts. A person may be able to get SSI if he has items worth no more than \$2000. A couple may be able to get SSI if they have items worth no more than \$3000. The Social Security Administration doesn't count everything you own. For example, these things are not counted:

- The home the person lives in and the land
- Life insurance policies with a face value of \$1,500 or less
- Usually the person's car, household goods, and personal property
- Up to \$1500 in burial funds

If the person works, there are special rules. The person may be able to keep getting some money from SSI while he works. But as he earns more money, his SSI payments may go down or stop. Some information on SSI work incentives is described later in this chapter.

Before a person can get SSI, he also must meet other rules. He must:

- Live in the U.S. or Northern Mariana Islands
- Be a U.S. citizen or national (some non-citizens can qualify for SSI)

People who live in city- or county-owned adult and/or nursing homes, halfway houses or other public institutions usually cannot get SSI. But there are some exceptions. For example, persons may be eligible if they live in a

- Publicly operated community residence that serves no more than 16 people
- Public emergency shelter for the homeless
- Public institution mainly for the purpose of attending educational or job training
- Public or private institution and Medicaid is paying more than half the cost of care

SSI Benefits for Children with Disabilities

The Social Security Administration considers the parents' income and assets when deciding if a child under 18 qualifies for SSI. This applies to children who live at home, or who are away at school but return home occasionally and are subject to parental control. When a child turns age 18, the Social Security Administration no longer considers the parent's income and assets when deciding if he or she is eligible for SSI. A child who was not eligible for SSI before his or her 18th birthday because the parent's income or assets were too high may become eligible at age 18. If a child with disabilities getting SSI turns 18 and continues to live with his or her parents, but does not pay for food or shelter, a lower SSI payment rate may apply.

Disability Determination

While the local Social Security Administration office decides if a child's income and assets are within the SSI limits, all documents and evidence pertaining to the child's disability are sent to the state's Disability Determination Service (DDS) unit at the Virginia Department of Rehabilitation Services. There, a team consisting of a disability examiner and a doctor reviews the child's case to decide if he or she meets the Social Security Administration's definition of disability.

If the available records are not thorough enough for the DDS team to make a decision, a parent may be asked to take his child to a special examination. The Social Security Administration will pay for the exam. It is important that you keep this appointment, or reschedule immediately, if needed. Failure to attend the examination, or invalid results due to poor effort, could result in an unfavorable decision.

The law states that a child will be considered disabled if he or she has physical or mental condition(s) that "very seriously limits his or her activities;" and

- The condition must last or be expected to last at least 12 months or be expected to result in the child's death; and
- The child must not be working at a job that is considered to be "substantial work." A job that pays more than \$1000 per month in 2010 is considered substantial.

To make this decision, the disability evaluation team first checks to see if the child's disability can be found in a special listing of impairments that is contained in the Social Security Administration's regulations. These listings are descriptions of symptoms, signs, or laboratory findings of more than 100 physical and mental conditions, such as cerebral palsy, intellectual disability, or muscular dystrophy, that are severe enough to disable a child. The child's condition does not have to be one of the conditions on the list. But, if the symptoms, signs, or laboratory findings of the child's condition are the same as, or "medically equal" in severity to the listing, the child is considered disabled for SSI purposes.

If the child's impairment(s) does not meet or medically equal a condition listed, the disability evaluation team then decides whether it is "functionally as serious" as one of the conditions on the List of Impairments. They assess the effects of the condition or combination of conditions on the child's ability to perform daily activities by comparing the child's functioning to that of children the same age who do not have impairments. To do this, they consider questions such as:

- What activities is the child able or not able to perform?
- Which activities are limited in comparison with those of same-age peers?
- What type and amount of help does the child need to complete age-appropriate activities?

To determine whether the child's condition "very seriously limits his or her activities," doctors and other trained staff review information and request the child's medical and school records and any other information needed to decide if the child is disabled. The information may come from doctors and other health professionals who treat the child, teachers, counselors, therapists, and social workers. A finding of disability will not be based solely on the parent's statements or in the fact that the child is or is not, enrolled in special education classes.

The disability evaluation process generally takes 3 to 5 months. However, the law includes special provisions for people (including children) applying for SSI disability whose condition is so severe that they are presumed to be disabled. In these cases, SSI benefits are paid for up to six months while the formal disability decision is being made. Some of the disability categories in which a child may be considered disabled and eligible for SSI payments are:

- HIV infection
- Total Blindness
- Total Deafness
- Cerebral Palsy
- Down Syndrome
- Muscular Dystrophy
- Severe Intellectual Disability (child age 7 or older)
- Birth Weight Below 2 Pounds, 10 Ounces

If a family receives these special payments, and later it is decided that the child's disability is not severe enough to qualify for SSI, the money does not have to be paid back.

Re-Determination

After a child starts receiving SSI, the law requires that the child's condition be reviewed to verify that he or she is still disabled. The continuing disability review (CDR) must be done:

- At least every three years for children under 18, whether or not their condition is expected to improve; and
- Not later than 12 months after birth for babies whose disability is based on a low birth weight; unless it is determined the condition is not expected to improve by the child's first birthday, in which case, the CDR is scheduled for a later date.

At the time a CDR is done, evidence must be presented that the child is and has been receiving treatment that is considered medically necessary and available for the child's medical condition.

Under the law, children who are receiving SSI benefits in the month before they turn age 18 must have their eligibility re-determined. The re-determination will be done during the one-year period beginning on the child's 18th birthday, or in place of a CDR, whenever it is determined that the child is subject to a re-determination. After age 18, to qualify for SSI as an adult, the person must have a physical or mental impairment, or combination of impairments, that is expected to keep him or her from doing any "substantial" work for at least a year or is expected to result in death.

The person's condition is compared to a listing of impairments that are considered to be severe enough to prevent someone from working for a year or more. If the person is not working and has an impairment that meets or equals a condition on the list, then he or she is considered disabled for Social Security purposes.

Monthly SSI payments are limited for residents of institutions where private health insurance pays for their care.

How to Apply for SSI for Your Child

An individual can complete an SSI application over the phone or make an appointment with a Social Security representative to complete an application at a local Social Security office. Parents or guardians can apply for a child under the age of 18 who is blind or disabled.

To begin the process, you must complete an application form and provide the required documents. Your financial information will be reviewed first by the Social Security office. The Child Disability Report may be completed online. If you prefer not to do this application on the internet, you can use any of the following ways to complete the report:

- Call the Social Security Administration's toll-free number, 1-800-772-1213, and explain that you want to file an SSI application on behalf of a child. (TTY number is 1-800-325-0778 for deaf/hard of hearing). Representatives are available Monday through Friday from 7 am to 7 pm.
- If you have a working printer, you may print a paper copy of the Disability Report - Child from the internet and mail or bring it to the Social Security office.

If financial criteria are met, your paperwork is referred to the Disability Determination Service, where a team will review medical documentation of your child's disability. Although the process can take a long time, the steps are not difficult. Be prepared, however, to provide detailed financial and medical information. You should try to collect as much of this information as possible prior to your appointment. This will help to speed the review process.

What to Bring to Social Security Office

Bring the following information to the Social Security office when applying for SSI for your child. This is in addition to the items requested in your application letter. Keep your appointment, even if you do not have all of the information. The Social Security representative may be able to help you get whatever is missing.

NON-MEDICAL INFORMATION:

- A list of all of the children and adults who live in your home, including their social security numbers.
- A list of your child's daily activities. You need to let Social Security know your child's current limitations in activities, such as: dressing, bathing, self-care, and interaction with others.
- An original or certified copy of your child's birth certificate. If the child was born in another country, bring proof of U.S. citizenship or legal residency.
- Your bank account statements, life insurance policies, certificates of deposit, stocks, or bonds.
- Your pay stubs, self-employment tax returns, unemployment or other program benefits, and child support.
- Names, addresses, and phone numbers of any schools your child attended in the past 12 months, including the names of teachers, psychologists, counselors, speech or other therapists who have seen or treated your child.
- Your mortgage payment information or rent receipts and landlord's name.
- Your child's Individual Family Service Plan (IFSP) or Individualized Education Program (IEP), if your child has one; and any other school records that you may have.
- A list of any social service programs and of caseworkers that have information about your child, including their names, addresses, and phone numbers.
- A list of any employers your child has had, including their names, addresses, and phone numbers.
- Name, address, and phone number of another adult who helps care for your child and can help the Social Security representative get information, if necessary.

MEDICAL INFORMATION:

- A list of every doctor, therapist, hospital, and clinic that has seen or treated your child for at least the last year, including their names, addresses, and phone numbers. Forms in Chapter 10 can help you organize this information.
- Medical records and other reports, including the dates your child was seen or treated and the child's patient ID number(s), if known. Call your child's provider and ask that they send these reports. You may need to make this request in writing, or complete a release form first. Ask how long it will take for the records to arrive, and follow up if you don't receive them.
- A list of medications and dosages. These can be found on the medicine containers.
- Your child's medical assistance number, if any.
- A list of your child's daily activities. You need to let the Social Security Administration know your child's current limitations in activities such as dressing, bathing, self-care, and interaction with others.

SSI Work Incentives

There are many rules that will help a person with a disability work and still get SSI benefits. Below are just two examples. For more information, call vaACCSES (1-877-822-2777) to talk to a benefits specialist or community work incentive coordinator.

PLANS FOR ACHIEVING SELF-SUPPORT (PASS)

Plans for Achieving Self-Support (PASS) is a SSI provision to help individuals with disabilities return to work. PASS lets individuals with disabilities set aside money and/or things he owns to pay for items or services needed to achieve a specific work goal. This can include things like supplies to start a business, school expenses, a computer, transportation, and training. PASS works by connecting the SSI recipient with a counselor or benefits specialist; deciding on a work goal; figuring out what items and services are needed to achieve that goal; and setting aside money for installation payments or down payments. If you are interested in PASS, please contact your local Social Security office for more information and forms.

STUDENT EARNED INCOME EXCLUSION

For young adults with special health care needs or disabilities, under the age of 22 and regularly attending school, the Social Security Administration will not count up to \$1,640 of earned income per month when they figure the student's SSI payment. The maximum yearly exclusion is \$6,600. These amounts are adjusted each year based on the cost-of-living so please check with your local Social Security office for the current exclusion amount.

Regularly attending school means that you take one or more classes in grades 7 – 12 for at least 12 hours per week; go to college for at least 8 hours per week; are in an employment training program at least 12 hours per week; or are home schooled.

How To File An Appeal

SUPPLEMENTAL SECURITY INCOME

If you wish to appeal, you must make your request in writing within 60 days from the date you receive a letter from the Social Security Administration denying SSI benefits. Call your local Social Security office if you need help with your appeal.

In some cases, your child's SSI benefits can continue while you are going through the appeals process. If you want your child's SSI benefits to continue, you must notify the Social Security Administration within 10 days of the date you receive their letter which says that they have received your appeal. If your appeal is turned down, you may have to pay back any money you were not eligible to receive. There are four levels of appeal:

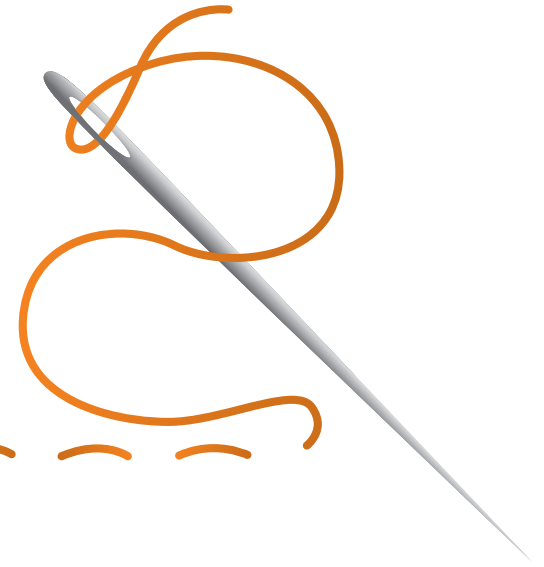
- **RECONSIDERATION:** A reconsideration is a complete review of your claim by someone who did not take part in the first decision.
- **HEARING:** If you disagree with the reconsideration decision, you may ask for a hearing. The hearing is conducted by an Administrative Law Judge. The hearing is usually held within 75 miles of your home. You and your representative (lawyer, medical expert, etc.), if you have one, can go to the hearing and explain your case in person. You can also look at the information in your file and give new information. After the hearing, the Social Security Administration will send you a letter with a copy of the judge's decision.
- **APPEALS COUNCIL:** If you disagree with the hearing decision, you can ask for a review by Social Security's Appeals Council. The Appeals Council looks at all requests for review, but may deny a request if it feels the hearing decision was correct. If the Appeals Council decides to review your case, it can decide your case itself or return it to an administrative law judge for further review. You will receive a letter from Social Security explaining what happened with your review.
- **FEDERAL COURT:** If you disagree with the Appeals Council's decision or if the Appeals Council decides not to review your case, you may file a lawsuit in federal district court. Remember, court action requires an attorney which can be expensive unless you are able to find an attorney willing to take your case on a contingency basis.



“ I used to say to them, 'He is not talking; he is not talking'. They never told me about Early Intervention. When he was four, I signed him up for preschool and the teachers said that he was not functioning like the other children and that he would need special education to get caught up. ”

Chapter 4

EARLY INTERVENTION, SPECIAL EDUCATION, SECTION 504 & COMPREHENSIVE SERVICES ACT



Early Intervention, Special Education, Section 504 & Comprehensive Services Act

There are systems of services available for children aged birth to twenty-two with special health care needs and disabilities through a variety of federal and state laws. This chapter will take a very brief look at four of those systems: Early Intervention, Special Education, Section 504 of the Rehabilitation Act of 1973, and the Comprehensive Services Act. Each of these systems serves a different age group, has its own eligibility criteria, and set of supports and services available.

Early Intervention

Under Part C of the federal Individuals with Disabilities Education Act (IDEA), Virginia provides early intervention services for children birth through two years of age who have an identified special health care need, disability, or who are not developing as expected. In Virginia, this system (called the Infant & Toddler Connection of Virginia) is comprised of 39 local lead agencies that plan how community agencies will provide early intervention services. To contact the point of entry in your community, visit www.infantva.org or call 2-1-1.

When a baby is referred to the Infant & Toddler Connection of Virginia, a service coordinator will work with the family to find out if he is eligible for services. A child is eligible for early intervention services if he has at least a 25% developmental delay or has a diagnosed disability that will probably result in a developmental delay.

If your baby is found eligible, the service coordinator will arrange an assessment to help you and a team of professionals learn about his strengths and needs in all areas of development. The information learned through the assessment will be used to write your baby's Individualized Family Services Plan (IFSP). The IFSP will include early intervention services available to meet your baby and family's needs such as:

- Assistive Technology
- Audiology
- Developmental Services
- Family Training, Counseling Or Home Visits
- Health Services
- Medical Diagnosis/Assessment
- Nursing
- Nutrition Services
- Occupational Therapy
- Physical Therapy
- Psychological Services
- Service Coordination
- Social Work Services
- Speech Language Therapy
- Transportation
- Vision Services

Some services are at no cost to you. You may be charged for other services based on your ability to pay – health insurance and Medicaid may pay for most of them. You will not be denied services because you cannot pay for them.

Special Education

Part B of IDEA specifies what Virginia must do to provide a free and appropriate public education for children aged two to twenty-two with developmental delays or disabilities. Because this chapter is intended only to provide a very brief overview of several laws and programs, a great resource, entitled "A Parent's Guide to Special Education," is available from Virginia's Department of Education (www.doe.virginia.gov/special_ed/parents/parents_guide.pdf).

THERE ARE 5 STEPS IN THE SPECIAL EDUCATION PROCESS:

1. IDENTIFICATION & REFERRAL

When you suspect your child has a delay or disability, a request for evaluation is given to the school. The school administrator must decide within three business days whether or not to evaluate your child. If the school decides not to evaluate your child, it must be in writing with the reasons for the decision not to evaluate. Please refer to the end of this chapter for information on how to file appeals.

2. EVALUATION

The school has 65 business days to evaluate your child to determine whether he has a disability as well as the nature and extent of the special education and related services he needs. You are part of the team that decides what information is needed for the evaluation (i.e., health, vision, hearing, social/emotional status, general intelligence, academic performance, communication, motor abilities, and adaptive behavior).

3. ELIGIBILITY

Based on the results of the evaluation, a team, including you, will meet to decide if your child is eligible for special education services. If you disagree with any results of the evaluation, you can request an Independent Educational Evaluation by qualified personnel who do not work for the school.

4. IEP

If your child is eligible for special education, a team, including you, will meet within 30 calendar days to develop an Individualized Education Program (IEP) to meet the needs of your child. The IEP team must consider the strengths of your child, any concerns you have about your child, evaluation results, academic and developmental needs, behavior supports, communication needs, and any assistive technology needs. Related services that could be incorporated in your child's IEP include: counseling services, interpretation, orientation/mobility services, physical, speech and occupational therapy, school health services, social work services, transportation, and vision services. A useful resource to help you and your child prepare for the IEP meeting is, "It's About Me: A Step-by-Step Guide for Creating My IEP," available from the Partnership for People with Disabilities at 804-827-0197.

5. REEVALUATION

At least every three years, a team, including you, will meet to reevaluate your child to determine whether he continues to need special education services.

Section 504

Section 504 of the Rehabilitation Act of 1973 is another federal law that protects children with disabilities, but in a different way. Section 504 prevents schools from discriminating against children with disabilities by removing barriers that keep children with disabilities from doing things that other children can do.

Section 504 applies to children aged five to eighteen who have a physical or mental impairment which substantially limits their ability to learn. Some examples include children with spina bifida, ADHD, diabetes, asthma, and learning disabilities. A parent can request an evaluation from the school. The same evaluation process used for special education is used for determining eligibility for Section 504.

The major difference between Part B and Section 504 is that an instructional education plan is not required. Under Section 504, a plan will be written that includes such services as, but not limited to:

- Accommodations (for example, a notebook of assignments, taking tests in a separate room, a chair near the teacher, a peanut-free environment, monitoring of blood sugar, wheelchair ramp, a tape recorder for notes)
- Counseling
- Health Services
- Sports
- Transportation

Comprehensive Services Act

Under the Code of Virginia, Virginia operates a funding stream to help troubled youth under the age of 21 with serious behavioral or emotional challenges (stemming from a variety of disabilities) and their families stay together. There are two categories of children and youth eligible to receive Comprehensive Services Act (CSA) services:

- **MANDATED** – children and youth eligible for special education who have an IEP requiring services to be provided in a private day placement or residential treatment center; children and youth in foster care; and children and youth at risk for foster care placement.
- **NON-MANDATED** – children and youth served by the juvenile court, a community services board, public schools, or other community agency. These children are not required to receive CSA services unless funding is available.

When a child/youth is referred to the local CSA office, a local team of foster care, special education, mental health, and juvenile justice professionals, as well as a family representative, will meet with the child and family to determine concerns, needs, and service requests. If found eligible, the team, including the child and his family, will write an Individual Family Service Plan (IFSP) that identifies the strengths and challenges of the child/youth and family, professionals already involved, and goals and recommended services to meet the goals.

Examples of CSA services include, but are not limited to:

- Evaluations & Assessments
- In-Home Counseling
- Inpatient & Outpatient Mental Health Care
- Mentoring
- Respite Care

Once the plan is approved, state and local government cover the cost of the services. More information on Virginia's Comprehensive Services Act can be found at www.csa.state.va.us.

How To File Appeals

It is important to remember that with all of these systems, you are an important member of the team designing services based on the needs of your child and family. Some teams meet quarterly, but at least annually, to review your child's plan. You do not have to sign any plan with which you are not comfortable. If the plan your child has is not working, you can call a meeting at any time to discuss making changes. You have the right to file appeals. If you want to talk to another parent who has navigated these systems, call 1-877-567-1122.

EARLY INTERVENTION

Written prior notice must be given to you within five calendar days before an agency or early intervention provider proposes or refuses to begin or change the identification, evaluation or placement of your baby, or provide appropriate services. The notice must detail the action that is being proposed or refused, the reason for taking the action, and the complaint procedure if you disagree. There are three methods for resolving disputes, all of which are available at no cost to you:

- **MEDIATION**

Call or write the Infant & Toddler Connection of Virginia to request mediation. The mediator will schedule the time and location of the meeting within 30 days of your request, and will help find a solution to the complaint that is fair and reasonable. If you feel mediation is unsuccessful, you may request a due process hearing.

- **IMPARTIAL DUE PROCESS HEARING**

You must submit a letter to the Infant & Toddler Connection of Virginia requesting an impartial due process hearing. Within 30 days of your request, the hearing must be held and a decision made. You have the right to be advised by an attorney (at your expense). If you are not satisfied with the hearing decision, you have the right to bring civil action in state or federal court and/or file an administrative complaint.

- **ADMINISTRATIVE COMPLAINT**

You must file your complaint with the Infant & Toddler Connection of Virginia within one year of the alleged violation. Within 60 days of your complaint, it will be investigated and a written decision provided.

SPECIAL EDUCATION

If you disagree with your child's identification, evaluation, educational placement, or the provision of a free and appropriate public education, there are three procedures commonly used:

- **MEDIATION**

Call or write the VA Department of Education (VADOE) to request mediation. The mediator will schedule the time and location of the meeting and will help find a solution to the complaint that is fair and reasonable. If you feel mediation is unsuccessful, you may request a due process hearing.

- **COMPLAINT**

You must write a letter to the VA DOE (with a copy to your school division) within one year of the violation and provide a statement of the violation, any relevant documents or supporting information, and a proposed resolution of the problem. The VA DOE must resolve the complaint within 60 calendar days. If you do not agree with their decision, you can file an appeal in writing within 30 days requesting a hearing.

- **DUE PROCESS HEARING**

You must send a request in writing to the VA DOE requesting a hearing. Your request must include the name of your child; his address; the name of his school; a factual description of the problem; and a proposed resolution of the problem. If the complaint is sufficient and not dismissed by the hearing officer (for failure to provide all required information), a resolution session will be held to try to resolve the dispute. After a 30-day resolution period, the hearing officer has 45 days to hold the due process hearing and mail a copy of the decision to you. Please note that if the school requested the due process hearing, not you, there is no requirement that the resolution session be held. If you do not agree with the hearing officer's decision, you have 180 days to file with state or circuit court and 90 days to file with federal court.

Visit www.doe.virginia.gov/special_ed/resolving_disputes/index.shtml for more information, forms and legal advocacy resources. You can also call the VA DOE Ombudsman for special education at (804) 371-7420.

More About How to File Appeals

SECTION 504

For issues related to the child's education, but not related specifically to identification, evaluation, or placement, you should submit a letter of grievance or complaint to the school principal or the school division's Section 504 compliance officer. The principal or Section 504 officer will investigate the situation to arrive at fair resolution.

An impartial hearing may be requested in writing to the school division's Section 504 coordinator or compliance officer by your student (if aged 18 – 22) or by you when there is a disagreement with the decisions made regarding the identification, evaluation, or placement of the student. You and your student may participate in the hearing and be represented by an attorney (at your expense). The hearing officer will provide you with a written decision based on the evidence presented at the hearing.

If you disagree with the decision of the hearing officer, an appeal may be filed with the school division in writing within one week of receiving the hearing decision. Typically, the school division's director of student services will serve as the reviewing officer. If you are still not satisfied with the decision, you may seek a decision through the court system (at your expense) or file a complaint with the Office of Civil Rights at the U.S. Department of Education at 1-202-208-2545.

COMPREHENSIVE SERVICES ACT

If you do not agree with decisions made in regards to your child or youth, you have the right to appeal. Your written appeal request must be submitted to your local CSA management team for their review. Contact your local CSA coordinator or your case manager for any special complaint forms or timelines.





“ When my son turned 18, the school told me we had to become his guardians or we could not come to IEP meetings any more. I learned all I could about this issue and discovered that he could sign a release of information allowing me to attend his school meetings. ”

Chapter 5

ALTERNATIVES TO GUARDIANSHIP



Alternatives to Guardianship

If your child will be turning 18 – the age of majority – in a few months, you may need to consider how you might support the decisions your son or daughter has to make as an adult. The freedom to make decisions plays an important role in defining all of us as human beings and Americans, and determining our quality of life. Some young adults will do a great job advocating for themselves, while others may need your involvement.

If your 18 year old cannot make decisions because of their disability, a court can remove their rights to make their own decisions and appoint someone else to make decisions for them. This is called guardianship. Guardians have the power to make decisions about where a person will live, work, spend their money, go, and dress. Removing a person's rights makes them more vulnerable, not less.

Guardianship should be an option of last resort and should be entered into only if it is determined that the individual has difficulty making appropriate decisions and does not have supports in place to manage his financial affairs, safety, and welfare. It is important to look at alternatives to guardianship that will put you in the role of a supported decision-maker with your young adult as he makes choices and lives a life that meets his needs. Different individuals have different situations, needs and available supports. Deciding what alternatives or guardianship options will work best in your child's unique circumstances can be complex and difficult. A good tool for you, your child, and his planning team to use to determine his level of ability with regard to key areas of his life and appropriate alternatives that meet his needs for support can be found on the Missouri Developmental Disability Resource Center website (www.moddrc.org). The questions on the tool are not intended to provide a final determination of what a person should, or should not, do in their unique circumstances, but rather a place to start the discussion. Below are some brief explanations of some common alternatives to guardianship.

Guardianship is a Last Resort

Since guardianship involves the loss of fundamental rights, it should be considered only when a person:

- Cannot make informed decisions on their own
- OR
- Cannot make informed decisions with accommodations or supports

HOW DO I KNOW IF MY CHILD NEEDS A GUARDIAN?

Here are just a few questions to think about when identifying a person's ability to make decisions and manage key areas of their life.

- Can the person look for and find a job?
- Is the person able to manage their money?
- Does the person make decisions about where, when and what to eat?
- Can the person take medications as directed?
- Is the person able to recognize when someone is taking advantage of them, hurting them or abusing them and protect themselves?
- Is the person able to make appropriate decisions concerning marriage and intimate relationships?
- Is the person able to be on their own without risk of serious harm or injury to themselves?
- Does the person understand what is involved with managing a home?
- Is the person able to understand and communicate consent and/or permissions regarding legal documents or services?
- Does the person demonstrate the ability to vote?
- Is the person able to decide and direct what kinds of assistance or support they need or want and select who provides those supports?
- Is the person able to communicate approval to share information with parents, family members and friends who are not legal guardians?

More About Alternatives to Guardianship

CONSENT FOR RELEASE OF INFORMATION

By signing a Consent for Release of Information Form, your adult child can now empower a family member or friend to participate in school meetings or other planning meetings, have access to records, and closely carry out his wishes. Most schools and agencies have their own consent forms.

REPRESENTATIVE PAYEE OR AUTHORIZED REPRESENTATIVE FOR SSI

The Social Security Administration has special paperwork and procedures for appointing a representative payee. Generally, a family member or friend may request and be appointed by Social Security to receive and manage your young adult's SSI benefits. The payee must follow strict rules to take care of the money.

POWER OF ATTORNEY

A Power of Attorney is a written document that can be limited, meaning your young adult gives permission to someone to act only with regard to a very specific matter like medical care. A Power of Attorney can also be general, meaning your young adult gives permission for someone to act of a wide variety of decisions (health, money, etc.). A Power of Attorney is only valid if the person signing understands the nature and importance of the document. A Power of Attorney can be revoked or modified at any time as long as the individual is determined competent.

Everyone is Presumed Competent to Make Choices About Their Lives.

Having a disability is not a reason to assume a person cannot make decisions. Sometimes, because of limited intellectual or communication skills, a person may simply need some help with making decisions.

More About Alternatives to Guardianship

CONSERVATORS

A conservatorship is a legal right given to a person to protect and manage the personal care or the assets and finances of a person deemed fully or partially incapable of handling these for himself. There are many circumstances where a person is still able to live an independent life, but may require help with his assets due to disability.

LIMITED OR JOINT BANK ACCOUNTS

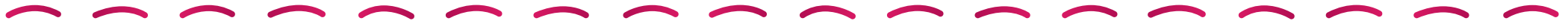
Most banks can help you set up limited or joint bank accounts to help ease concerns about money management. Some additional features may include pre-set limit debit/credit cards or dual signatures on checks.

MICROBOARD

A microboard is a small group of committed family members and friends who join with your adult child to form a circle of support and create a non-profit corporation. Since the microboard is a legal entity, its purpose is to ensure that your adult child's circle of friends will endure. The microboard provides support to and decision-making assistance with your adult child, and ensures that he has opportunities to participate in the community in as many ways as possible. In addition, microboards make sure the supports and services your adult child receives are individualized to meet his needs. For more information on microboards, visit http://www.communityopportunities.org/index_files/Page383.htm.

Don't Be Afraid to Get Legal Advice.

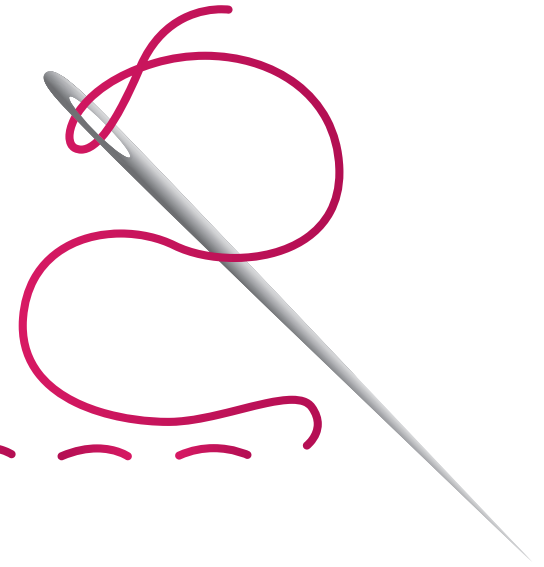
It is important to note that some of the alternatives to guardianship may provide less protection for your young adult, so it is always best to speak with an attorney. Your State Bar Association (1-804-775-0500), Legal Aid (1-866-534-5243), or the Virginia Office for Protection and Advocacy (1-800-552-3962) is a good place to start when looking for legal advice.



“ My daughter has a medical home at her pediatrician’s office. All the doctors there have seen her. So for me, there has never been a single problem if I am not going to have the same doctor each visit because all of them are well aware of her condition. ”

Chapter 6

FAMILY-CENTERED CARE & MEDICAL HOME



Family-Centered Care

Children's health is rooted in the family. Family-centered care recognizes the parents' role in their children's health and health care. Good family-centered care relies on a positive relationship between families and professionals caring for their child. A mutually respectful and collaborative partnership promotes good communication, goal setting, and problem-solving. This collaboration enables families to increase their health knowledge and skills as well as take responsibility for their children's health. When it works well, everyone benefits, especially the child.

FAMILY-CENTERED CARE

Family-centered care is grounded in a mutually respectful and collaborative partnership among children, patients, families, physicians, nurses and other professionals for the planning, delivery and evaluation of health care as well as in the education of health care professionals. These collaborative relationships are guided by the following principles:

- Respecting each child & his/her family
- Honoring racial, ethnic, cultural & socio-economic diversity and its effect on the family's experience & perception of care
- Recognizing & building on the strengths of each child & family, even in difficult & challenging situations
- Supporting & facilitating choice for the child & family about approaches to care & support
- Ensuring flexibility in organizational policies, procedures & provider practices so services can be tailored to the needs, beliefs & cultural values of each child & family
- Sharing honest & unbiased information with families on an on-going basis & in ways they find useful & affirming
- Providing and/or ensuring formal & informal support (i.e. parent to parent support) for the child & parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence & young adulthood)
- Collaborating with families at all levels in the care of the individual child
- Empowering each child & family to discover their own strengths, build confidence and make choices & decisions about their health

If you need help, don't be embarrassed.

Let professionals in your child's life know what your needs are – don't be afraid to ask for help.

FAMILY & PROFESSIONAL COLLABORATION

- Promotes a relationship in which family members & professionals work together to ensure the best services for the child & the family
- Recognizes & respects the knowledge, skills & experience that families & professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship
- Recognizes that negotiation is essential in collaborative relationships
- Facilitates open communication so that families & professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values & diversity of families is acknowledged & honored
- Brings to the relationship the mutual commitment of families, professionals & communities to meet the needs of children with special health care needs & their families

Knowing how to interact with professionals can be critical to your success as an advocate for your child.

FOUR HABITS OF HIGHLY EFFECTIVE FAMILY & PROFESSIONAL PARTNERSHIPS:

- **BE PROACTIVE**
Adopt an attitude that is collaborative and responsible.
- **BEGIN WITH THE END IN MIND**
Be able to envision the future & the possibilities for your child.
- **PUT FIRST THINGS FIRST**
Prioritize what is most important or urgent in the coming year.
- **SEEK FIRST TO UNDERSTAND & THEN TO BE UNDERSTOOD**
Listen to professionals. You don't have to always agree but to understand their viewpoint.

Medical Home

Children and youth with special health care needs and disabilities deserve the same level of regular health care that other children receive. Often finding primary care providers where the family lives that are able to understand the child's chronic condition and how it affects their entire life can be difficult.

A Medical Home is not a building or a house. The Medical Home concept is a way for you and your child's doctor to work together. A Medical Home teams you with your doctor to plan for and meet your child and/or youth's special needs. When you have problems finding resources in your community or coordinating your child's specialist visits, the doctor and staff in your Medical Home are able to help you. Being family-centered, they know your family's needs and understand your child or youth.

A Medical Home:

- Has a caring attitude
- Is able to listen & welcomes your questions
- Knows your child & your family, including your names!
- Has a willingness to try things differently to meet your family's needs
- Allows for hope
- Helps your child to grow, learn, play, laugh & love

The relationship that the Medical Home has with your family is important in assisting the child as they meet challenges in life. The Medical Home doctor knows the child and can provide timely referrals to early intervention programs, school and childcare. By doing this, families are able to get support when they need it. For example, most children with special health care needs can go to community child care, but sometimes it helps to have the doctor work with the child care provider so they know how to care for the child's special needs. Or when the school does not understand your child's needs, it helps to have the doctor talk with the school to explain your child's special needs. Ideally, the medical home, schools, and community agencies work together to help families and their children reach their goals.

Medical practices in Virginia are actively working to improve care for children with special health care needs. The Virginia Chapter of the American Academy of Pediatrics, the Virginia Department of Health, the Virginia Community Healthcare Association, and Medical Home Plus, Inc. are working to improve access to care for children with special health care needs and disabilities. They are training doctors and other community providers about the Medical Home concept so children and youth are healthy and happy in their community.

For more information about Medical Home, contact the National Center for Medical Home Implementation (1-800-433-9016 or www.medicalhomeinfo.org) or Medical Home Plus, Inc. (1-877-264-8366 or www.medhomeplus.org).

A Medical Home has the Following Qualities:

ACCESSIBILITY

- Care is available 24 hours a day, 7 days a week through an “on-call” doctor
- Care is provided in the family’s community of choice
- The office space & equipment is accessible to the child

FAMILY-CENTERED MEDICAL HOME STAFF MEMBERS

- Know you & your child well
- Are able to make accommodations for your child’s special needs
- Show respect
- Ask your opinion

CONTINUITY

- Provides a primary health care provider who routinely sees the child at most visits
- Understands change & guides the family & child through the ages & stages of growing up

COMPASSION

- Understands & expresses concern for the child & the family

COMPREHENSIVE CARE

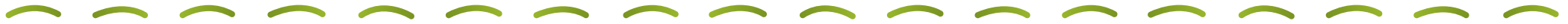
- Cares for your child as a whole person, not just a disability or diagnosis
- Makes sure that your child has their shots
- Understands your child’s special condition & how that makes a difference in their life

COORDINATION

- Collaborates with other providers & agencies to ensure that your child’s needs are met
- Works with your insurance company to make sure your child gets what he or she needs
- Works with the family & child to develop a plan with goals to help plan the way

CULTURAL COMPETENCY

- Provides information to you that is understandable both verbally & written
- Gets interpretation & translation services if needed
- Values & respects differing cultural backgrounds



“ Through this process, I was able to gather what I and others knew and loved about my son and it has changed the way people support him. ”

Chapter 7

THIS IS MY LIFE: CREATING A LIVING DESCRIPTION



Creating a Living Description

Throughout your child's lifetime, he will come into contact with many physicians, healthcare professionals, teachers, support coordinators, employment specialists, therapists, community members, and employers. Each of them will have a special body of knowledge according to their profession. They will have expertise in their field but will never know your child as well as you. Creating a written, living description with and about your child is one way you can share the unique information that describes your child with others.

A LIVING DESCRIPTION IS:

- An ever-changing document that has information about your child with disabilities or special health care needs
- Done **with** your child, not for them
- Unique to your son or daughter
- Created as a result of listening to your child & others who know & love them
- Easy to do & does not need a professional to facilitate the process of gathering information

A LIVING DESCRIPTION MAY BE USED:

- To help your child get a better life, according to how he defines it
- To recognize what gifts & capacities your child brings to the community
- To put intentional focus on what is **important to** your child
- To help healthcare professionals, teachers, job coaches, employers & others better support your child
- As the foundation on which to build friendships, relationships & belonging in the community
- To guide the development of life & educational goals, therefore becoming the basis on which a formal or informal plan may be made

There are numerous resources and templates that can help you create a living description with your child along with ways to use the information to develop an action plan. Although each approach has unique features, they are all rooted in the principles of self-determination. Self-determination means giving people with disabilities and special health care needs the opportunity to steer their own boat — to be captains of their own ship. A good resource on self-determination is www.centerforself-determination.com.

Your Child will Grow & Change in Many Ways.

With your child, revisit their living description periodically to see what needs to be added and what needs to be taken off.

The Principles of Self-Determination

CHOICE

People have the right to choose how they will live their lives, where and with whom. When people need help, it is friends and family closest to them who assist them in broadening their experiences and exercising their right to choose. It is essential that each person have a circle of support chosen by them.

RELATIONSHIPS

The relationships a person has with others are like precious gems. A relationship must be treasured, nurtured, and protected.

CONTRIBUTION & COMMUNITY

Everyone has the ability to contribute to his or her community in a meaningful way. Giving of self helps people establish a sense of belonging and identity.

RESPONSIBILITIES

Individuals, as they take greater control and authority over their lives and resources, assume greater responsibility for their decisions and actions. Professionals and staff work for the individual, rather than for the system. Families, friends and staff assist people in creating more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help make dreams come true while never forgetting who is in charge.

CONTROL

People have the power to make decisions and truly control their lives. This includes gaining authority over financial resources and the power to determine what supports are necessary, how they will be implemented, and by whom. People also have control of hiring those who will provide support.

DREAMING

All people have hopes and dreams which guide the actions they take and are the most meaningful to them. A commitment to helping people determine their dreams, respecting those dreams, and helping make dreams come true is crucial.

DIGNITY & RESPECT

All people have the right to be treated with dignity and to be respected as a whole person. Some of life's greatest lessons are learned by making choices that are later realized to have been mistakes. All people have the right to the dignity of risk.

FISCAL CONSERVATISM

Making things happen does not always require money. It is important that alternatives to paid support be found. Communities offer many informal resources — faith-based youth groups, boys and girls clubs, YMCA programs — with which your child can be connected.

WHATEVER IT TAKES

The attitude, "nothing is impossible, as long as it is legal and causes no harm," is required. "No we can't," as an answer is replaced by, "How can we make this happen?"

More on Creating a Living Description

Among the most widely used approaches to creating living descriptions and plans are Making Action Plans (MAPs), Planning Alternative Tomorrows with Hope (PATH), Personal Futures Planning, and Essential Lifestyle Planning (ELP). MAPS is about listening to a person's dreams, acknowledging their nightmares, then building a rich portrait of their gifts and talents so the person and their support team can focus on simple daily actions. PATH is a creative planning tool which starts in the future and works backwards to beginning steps which are possible and positive to meet that goal in the future. Personal Futures Planning promotes the positive futures and images of people with disabilities and shows that all of us count and all of us fit somewhere. ELP is a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow.

As a family member, you can create a basic living description with and about your child that will be a resource for you in a variety of settings. The document is called a living description because it will need to be updated as your child grows and changes. This is not a one-time activity, but one that is on-going as more information is gathered and as changes in your child's life occur. If your child does not use words to communicate, you can make the best guess based on your close relationship with your child, on what to put into the description. At the end of this chapter, you will find an example of Brooke's one page living description developed from the forms you will find at the end of chapter 10. Additional examples of living description can be found at The Learning Community for Person-Centered Practices — visit http://www.learningcommunity.us/sample_plans.htm and at <http://www.inclusive-solutions.com/pcplanning.asp>.

Information for a living description comes from your child, yourself as a parent/guardian and others who know and love your child. Information is gathered through conversations with your child and with those who are important in your child's life. Conversations may take place in person, on the phone, through email or in a group. Some people hold an information-gathering party, inviting people their child wants and making it a celebration. Once information is gathered, your child has the final say over what is included in his description.

What is in a Living Description?

Every living description includes your child's **hopes and wishes** for the future. The future may mean next week, next year or years from now. It may also include your hopes and wishes for your child. Hopes and wishes may be small or large. They may be as varied as wanting to be a veterinarian, a desire to go to Disney, saying a first word, or a child making eye contact. Just like any one of us, hopes and wishes change over time and the changes will need to be reflected in the description.

Thinking about hopes and wishes may be difficult for some parents especially when healthcare needs feel overwhelming or when your child is newly diagnosed. And sometimes your child will want something they may never achieve. If you think about your own life, ask yourself, "Have I achieved every dream of mine? Did I learn from the journey toward reaching for a particular goal?" The additional components of a living description that are described below come from The Learning Community for Person-Centered Practices.

Sometimes a child with healthcare needs or a disability becomes identified by the label they have, and at times they are seen by others according to what they can't do. One part of a living description can capture all the capabilities and gifts your child possesses. Ask your child what he does well. Think about what you love about your child. Talk to family, friends, teachers and others who know your child and ask what they **like and admire about your child**. Ask them what they see as your child's gifts and strengths. Then review the list and ask your child which descriptions he wants to include in their description.

A **relationship chart** documents the people in your child's life. Besides providing a snapshot of your child's current relationships, this component of the living description helps determine where more relationships need to be developed. Often, we find that people with disabilities and significant healthcare needs have a lot of people who are paid to be in their life and not as many unpaid friends. When filling in a relationship chart, have your child consider who he would include in each section and begin each category with the name of the person to whom he feels closest. Sometimes it helps if you recreate the relationship chart on bigger paper and use pictures of each person, having your child place them where they belong on the chart.

Professionals in service systems are very good at providing what is important for your child. "Important for" are those things that keep people healthy and safe. Too often what is **important to** your child gets overlooked. A living description can provide this information. "Important to" includes things that make your child happy and content. It includes, among other things, people, pets, routines and rituals, products and things, interests, hobbies, what he likes to do and places he likes to go. All humans need things in their lives that are important to them. Having just a little of what makes us happy, helps to deal with life's inconveniences and stressors. The challenge often comes from finding the balance between what is important to and what is important for.

Another part of a living description can be **instructions for support**. This can be very detailed or more general depending on your child's needs. In some instances, the instructions will mean the difference between health and a health crisis. In others, instructions for supporters will mean the difference between a good day and a bad day for your child. Instructions for supports could address what others need to know or do to keep your child healthy and safe. One way to start thinking about this information is what Smull, Allen, and Bourne describe in their training, *Families Planning Together* (2001) as the Two Minute Drill. Imagine you have an emergency and suddenly have to leave.

The person who will 'fill in' has arrived and you have two minutes to give advice, suggestions, or tips about supporting your child. What would you say? Instructions for support can also include instructions for others on how to best support your child that doesn't have to do with health and safety. One way to start thinking about this is considering what is called Good Day/Bad Day. Make a list of things that would contribute to a good day for your child and make a list of what a bad day looks like for your child. There may be things on these lists that can be added to your child's "important to" list or "instructions for supporters."

A living description can include any information that you think would be helpful to others to know and support your child better. Other types of information that could be included are:

- A list of your child's doctors with contact information, the medications prescribed, what the medication is for;
- Characteristics of people who would support your child best;
- A chart that describes how your child communicates, especially if they do not use words to communicate; and
- Fears/worries, things your child doesn't like.

Me

My name is Brooke
I live in Virginia with my mom and dad
I go to Varina High School
I want to own a doggie day care
when I graduate high school

My Strengths & Talents

I can occupy myself for long periods of time
I pay attention
I am physically strong

Words That Describe Me Best

Always cheerful
Inquisitive
Funny
Cute

What You Can Do to Help Me

Pour drinks in my cup
Put food on a fork for me
Help me to the bathroom, get dressed
Help me at school "talk" to classmates
Help me understand and do activities
Push my wheelchair
Give me clear and simple directions
Hold things close to me so I can see them



My Favorite Things

My favorite foods are chicken nuggets, potatoes
and peanut butter crackers — and sweet ice tea
I like riding in the car with the
window open blowing my hair
I love the sound of a shaking bottle of water
I like listening to music (pop, rock and rap)
I love going to Florida to visit my grandparents

An Ideal Day

A big breakfast with OJ
Going to school
Quiet time throughout the day
Eating every couple of hours
Lots to drink
Sitting with friends in class or lunch
Chillin' in my room
Playing or shopping with my mom and dad

My Fears & Worries/ Things I Don't Like

Sudden noises
When I don't know what's going to happen next
Angry, loud voices
Being ignored
Bright sun or lights in my eyes
Not having my dog (she died)

My Worst Possible Day

Sitting at home all day with nothing to do
Not getting enough to eat or drink
Being ignored — especially
when I use my body to "talk"
Having surgery



“ The turning point in my daughter’s IEP team was when we committed to being open, respectful, and trusting of one another. ”

Chapter 8

BUILDING & MAINTAINING EFFECTIVE PLANNING TEAMS



Building & Maintaining Effective Planning Teams

In Chapter 6 we discussed the importance of family/professional collaborative relationships. Effective medical and educational planning for children with special health care needs requires meaningful parent participation in the development of a child's goals. In order to be the best advocate for your child, it is critical that you work effectively together with his or her medical and education teams, with both shared goals and mutual respect. This requires building and maintaining strong relationships with the key people involved with your child.

5 Reasons to Advocate for Your Child:

- You know your child best
- You have the unique ability to understand your child's needs
- You are responsible for your child's welfare
- You are a role model for your child
- You have the right to make decisions on your child's behalf

Identify Key Players

The first step in the process of building strong relationships is to identify the key players in the process. Typically, along with yourself and your child, members of medical and education teams include physicians, nurses, specialists, case managers, therapists, special education teachers, general education teachers, and administrators. Consider anyone who can be a resource for you in navigating the medical or education systems. As you identify the key players in the process, keep a list of their names, contact information, and the role they play.

Establish Relationships

The key to building strong relationships with medical and education professionals involved with your child is approaching each relationship as a professional one. It is critical to set the tone from the start with professionals, especially in your on-going dialogue during the course of appointments and meetings.

- Arriving on time, following-up on discussions, and being an active participant in the discussion are essential to creating a professional tone.
- Approach each key person as an expert in his or her field. They have valuable experiences to bring to the table.
- Acknowledge their ideas and suggestions and do not be afraid to offer your own ideas and input.
- Discussions with medical and education professionals about your child's plans are often difficult and can become highly emotional. To the degree possible, effective advocacy requires containing those emotions during the discussions so that you can better focus on the issues at hand.
- Before appointments and meetings, outline what you have in mind for your child and send it to the team members so that they have an opportunity to review your ideas and goals in advance.
- It is helpful to bring someone with you who can listen and take notes.

Be Prepared for Your Team Meeting

Below is a checklist of things you might consider doing before, during and after your team meetings to ensure that you are a collaborative member of the team.

BEFORE A TEAM MEETING

- **BE PREPARED**

Prior to any meeting, always identify your objective. Make a list of your goals and what you hope to accomplish at the team meeting.

- **BAKE COOKIES**

Bring food, cookies, chocolate or fruit to your team meetings. It not only lightens the mood, but it gives you something to stick in your mouth if you feel the need to say something you might regret later.

- **INVITE A FRIEND**

If appropriate, invite a family member, friend or advocate to the meeting. Having someone at the meeting for support enables you to stay focused.

- **BE ON TIME**

Plan ahead so that you can arrive on time for your child's team meeting. If you are going to be late, be courteous and call to let someone know when you will arrive.

DURING A TEAM MEETING

- **CELEBRATE**

Start every meeting with members sharing celebrations in their lives.

- **BE RESPECTFUL**

Be considerate of other team members, even if their views conflict with yours. Be careful with your words and actions, especially when you are upset.

- **ASK QUESTIONS**

Remember the saying "there is no dumb question". If you do not understand something that is being discussed, ask questions.

- **LISTEN**

You cannot listen with your mouth moving. Let other team members know you are listening by looking at the speaker, nodding occasionally and not carrying on side conversations.

- **TAKE NOTES**

Jot down important comments and decisions made and tasks assigned. This gives you a record to reflect upon after the meeting.

AFTER A TEAM MEETING

- **WRITE THANK YOU NOTES**

If a member of the team really supported you at the meeting, show them that you really appreciate it by writing a quick thank you note. If you are upset with a team member, call and ask if they would like to meet for lunch so you can spend some time discussing their comments, their feelings and their opinions.

- **COMPLETE ASSIGNED TASKS**

If you agreed to do something before the next meeting, be a responsible member of the team and complete the task. If you are having difficulty with the task, call a member of the team for help.

- **EVALUATE WHAT WORKED WELL & WHAT DID NOT WORK WELL**

To improve the outcome of future meetings, always revisit your list of goals and accomplishments you anticipated from this meeting. If you were successful, why? If you weren't, why not? Discuss the successes at the next meeting.

Maintain Relationships

Like any relationship, your relationships with medical and education professionals must be maintained. Many of these professionals will be interacting with your child on a regular basis throughout his or her life. Maintaining relationships is an on-going process. Written statements about your concerns and what you would like to see changed are critical. Likewise, sending letters when you are happy with the way things are progressing is important.

Remember, you are an equal partner in developing your child's medical and education plans. Be prepared to give input and listen respectfully to other ideas. To be an effective member of the team, remember the following tips:

- **OPEN TO PERSUASION**
Be open to suggestions, not that things should be "my way or no way." Other team members might have information or access to information that you don't have.
- **COOPERATE**
If everyone agrees to vote in a way that you don't agree with, let it go and move on if possible. If you cannot let it go, be careful with your words and actions, especially when you are upset. Remember that this medical or education team may be together for a long time.
- **RESPECT**
Be considerate of other team members, even if their views conflict with yours.
- **GOOD LISTENER**
Let other members know that you are listening and that you understand by looking at the person speaking, nodding occasionally, and not carrying on separate conversations with the people at the table next to you.
- **ASK QUESTIONS**
If you do not understand something being discussed, ask for clarification.

Repairing Damage

Many parents experience intimidation and frustration in trying to work with medical and education specialists. If there has been a bad experience with team members in the past, it is crucial that you attempt to move forward in a positive way.

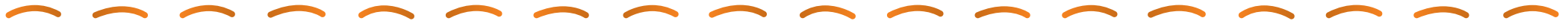
The best way to repair any damage is to openly acknowledge the problem. Be forthcoming about the tension that has occurred in the past and your desire for a more positive and productive working relationship. Be candid about what you believe would help to facilitate a better experience in the future. Keep a record of these attempts, especially if you are unable to resolve the issue and need to pursue other avenues in your advocacy efforts.

The Art of Negotiation

Conflict is inevitable — a wife and husband at odds over how to share housework; a father and daughter arguing over the use of the family car; a parent's job is at stake because he or she regularly misses work due to their child's illnesses; an employee is resentful of their bosses for a heavy work load; and, the conflict we sometimes find when we sit down at the medical or education team meeting. Disagreements happen because everyone has different values, opinions, and goals.

Compromise is reached when everyone gives something up to gain a common solution — no one wields more power or control than another. Your relationships in life are shaped by how well you are able to manage and negotiate conflicts.

People resolve disagreements in many ways. The bargaining style is a win-lose approach. One party wins at the expense of another. The lose-lose approach is about "if I don't win, neither should you." Everyone comes out a loser. Compromise is when "you give some, I give some;" which makes the win-win approach the ideal negotiation solution. The needs of all parties are satisfied by having all creative options on the table, thoroughly explored.



“ Getting connected to resources was what I really needed. The information helped me feel more confident about advocating for my son. ”

Chapter 9

RESOURCES



Child & Family Resources

BRIGHT FUTURES

Bright Futures is a national health promotion initiative dedicated to the principle that every child deserves to be healthy and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community as partners in health practice.

(804) 864-7768 • (804) 864-7685

www.brightfutures.org (national) • www.vahealth.org/brightfutures

CARE CONNECTION FOR CHILDREN (CCC)

Care Connection for Children is a statewide network of Centers of Excellence for children with special health care needs (CSHCN) sponsored by the Virginia Department of Health.

Children are eligible to receive Care Connection services if they are residents of Virginia under the age of 21, and have a chronic physical condition that requires health care and other services beyond that which is needed by children generally. Services are free of charge. Each of the six CCC centers serves a large geographic area.

www.vahealth.org/specialchildren/cccprogram

- Blue Ridge (866) 596-9367
- Central Virginia (866) 737-5965
- Hampton Roads (800) 864-8903
- Northern Virginia (866) 222-0372
- Roanoke Area (866) 906-2999
- Southwest Virginia (800) 704-1285

CENTER FOR FAMILY INVOLVEMENT (CFI)

The CFI is funded by state and federal grants and supports families and professionals in working together toward a common mission and vision with the ultimate goal of improving life outcomes for people with disabilities and their families.

(877) 567-1122 • www.centerforfamilyinvolvement.org

CENTERS FOR INDEPENDENT LIVING (CIL)

CILs are non-profit organizations that provide services to persons with significant disabilities to maximize their independence. Services include information and referral, independent living skills training and advocacy training. They also provide information and technical assistance to the community. CILs are non-residential places. There are sixteen CILs in Virginia.

www.vadrs.org/cbs/cils

CHILD DEVELOPMENT SERVICES

The Child Development Services (CDS) program is a statewide network of clinics sponsored by the Virginia Department of Health. The clinics serve children and adolescents suspected of having developmental and behavioral disorders. The clinic team consists of a pediatrician, nurse, social worker, educational consultant and psychologist. Services include diagnostic assessment and care planning, care coordination and referral. Each CDS clinic serves a large geographic area:

www.vahealth.org/specialchildren/cdsprogram

- Danville (434) 797-1040
- Fredericksburg (540) 891-3151
- Gate City (276) 386-3803
- Harrisonburg (540) 568-6687
- Lynchburg (434) 947-2030
- Norfolk (757) 683-8770
- Richmond (804) 827-2100
- Roanoke (540) 224-4520
- Winchester (540) 722-3484

More Child & Family Resources

COUNCIL FOR EXCEPTIONAL CHILDREN (CEC)

The Council for Exceptional Children is the largest international professional organization dedicated to improving educational outcomes for students with disabilities and/or the gifted. CEC sets professional standards, provides professional development and advocates for appropriate governmental policies. An excellent resource for information on the IDEA.

(888) 232-7733 • www.cec.sped.org

COURT APPOINTED SPECIAL ADVOCATE PROGRAM (CASA)

CASA is a child advocacy program that assigns trained volunteers to speak for abused and neglected children in the juvenile justice system. There are more than 25 local CASA programs.

(434) 528-2552 • www.cvcasa.org

EASTER SEALS

Easter Seals North Carolina & Virginia provides programs, services, consultation, advocacy and education for children and adults with disabilities, their families and their communities.

(800) 662-7119 • www.nc.eastersealsucp.com

FAMILY INVOLVEMENT PROJECT (FIP)

The Family Involvement Project is a program of The Arc of Virginia. FIP works to assure that Virginia's Infant and Toddler Connection program is of the highest quality. The project focuses on strengthening family involvement with local interagency coordinating councils.

(888) 604-2677 • www.arcfip.org

FAMILY TO FAMILY NETWORK OF VIRGINIA

The family to family network, Virginia's Family to Family Health Information Center, provides one to one support through regional hubs for families navigating the disability services systems.

(877) 567-1122 • www.centerforfamilyinvolvement.org

FAMILY VOICES

FamilyVoices is a national grassroots network of families and friends that advocates for health care services for children and youth with special health care needs. FamilyVoices promotes inclusion of families as decision-makers at all levels of health care and supports essential partnerships between families and professionals.

www.familyvoices.org

LEGAL AID

Legal aid provides legal assistance to low income people.

(866) 534-5243 • www.valegalaid.org

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

NICHCY is funded by the federal Office of Special Education Programs of the Department of Education to connect families to needed resources for infants, toddlers, children and youth who have disabilities. All information through NICHCY is available in both English and Spanish.

(800) 695-0285 • www.nichcy.org

NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

NORD is a non-profit health organization dedicated to helping people with rare diseases and assisting the organizations that serve them. NORD provides information, education, referrals, advocacy, research grants and Medication Assistance Programs.

(203) 744-0100 • (800) 999-6673 (voice mail only) • www.rarediseases.org

PARENT TO PARENT OF VIRGINIA (PTPofVA)

PTPofVA, Virginia's state Parent to Parent office, supports families with children with disabilities and service providers across the Commonwealth with best practice in family support. PTPofVA provides training, technical assistance and advocacy support. For a national list of Parent to Parent programs, visit Parent to Parent USA.

(804) 828-0352 • www.ptpofva.com • www.p2pusa.org

More Child & Family Resources

PARENT TRAINING & INFORMATION CENTER

The Parent Educational Advocacy Training Center (PEATC) assists families of children with disabilities through education, information and training. PEATC builds parent-professional partnerships to promote success in school and community life. (800) 869-6782 (VA only) • www.peatc.org

SPECIAL NEEDS ADVOCATE FOR PARENTS (SNAP)

SNAP offers a number of services (medical insurance assistance, resources, newsletter, special needs estate planning) to parents who have children with special needs to help them make important decisions in planning for their child's well-being as well as to provide information, resources and networking opportunities. (888) 310-9889 • www.snapinfo.org

SPECIAL NEEDS ASSISTANCE PROGRAM FOR CHILDREN (SNAP4KIDS)

Assists families through information, referral and education. Provides modest grants for medical and therapeutic equipment not covered by insurance. (757) 440-5254 • www.snap4kids.org

SPECIALIZED TRAINING OF MILITARY PARENTS (STOMP)

Parent training and information center established to help military families who have children with special education or health care needs. (800) 572-7368 • (800) 5-PARENT • www.stompproject.com

UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

The Partnership for People with Disabilities operates more than 20 federal and state programs supporting individuals with disabilities and families, including the Center for Family Involvement and the Center for Self-Advocacy Leadership. (804) 828-3876 • www.vcu.edu/partnership • www.virginiaselfadvocacy.org
www.centerforfamilyinvolvement.org

VIRGINIA POVERTY LAW CENTER (VPLC)

The Virginia Poverty Law Center is a non-profit organization concentrating in areas of law that affect low-income families. VPLC provides training to local legal aid programs, attorneys, and low-income clients, relating to the legal rights of Virginians living in poverty. The website includes a legal services directory for Virginia. (800) 868-8752 • (804) 782-9430 • www.vplc.org

WOMEN, INFANTS & CHILDREN PROGRAM (WIC)

The WIC program is a supplemental nutrition program funded by the U.S. Department of Agriculture. WIC provides high-quality food to pregnant and lactating women and children up to the age of five. It is operated through local health departments and mobile clinics throughout Virginia. (888) 942-3663 • (888) WIC-FOOD • www.vahealth.org/wic

Virginia State Agencies

ASSISTIVE TECHNOLOGY

Virginia Assistive Technology System & New Well Fund
(804) 662-9990 • (800) 435-8490 • www.vats.org

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Virginia Department of Health
(804) 864-7706 • www.vahealth.org/specialchildren

DEVELOPMENTAL DISABILITIES

Virginia Board for People with Disabilities
(804) 786-0016 • www.vaboard.org

HEALTH INSURANCE (COMMERCIAL)

Virginia State Corporation Commission, Bureau of Insurance
(800) 552-7945 • www.state.va.us/scc/division.boi

DEAF/HARD OF HEARING

Virginia Department for the Deaf & Hard of Hearing
(800) 552-7917 • www.vddhh.org

INFANT & TODDLER CONNECTION OF VIRGINIA

Virginia Department of Behavioral Health & Developmental Services
(804) 786-3710 • www.infantva.org

MEDICAID (INCLUDES FAMIS PLUS & FAMIS)

Virginia Department of Medical Assistance Services
(866) 873-2647 • www.dmas.virginia.gov • www.famis.org

PROTECTION & ADVOCACY

Virginia Office for Protection & Advocacy
(800) 552-3962 • www.vopa.state.va.us

REHABILITATIVE SERVICES

Virginia Department of Rehabilitative Services
(800) 552-5019 • www.vadrs.org

SOCIAL SERVICES

Virginia Department of Social Services
(804) 726-7000 • (800) 552-3431 • www.dss.state.va.us

SPECIAL EDUCATION

Virginia Department of Education
(800) 225-3252 • www.doe.virginia.gov

VISUAL IMPAIRMENT & BLINDNESS

Virginia Department for the Blind & Vision Impaired
(804) 371-3140 or (800) 622-2155 • www.vdbvi.org

Disability-Specific Organizations

A.D.D. & A.D.H.D.

CHILDREN & ADULTS WITH ADD/ADHD

CHADD works to improve the lives of people affected by AD/HD through leadership, advocacy, research, education, and support.

(800) 233-4050 • www.chadd.org

Autism

COMMONWEALTH AUTISM SERVICES

Provides leadership in the implementation of a statewide system of services to maximize the potential and quality of life of Virginians with autism.

(800) 649-8481 • www.autismva.org

VIRGINIA AUTISM RESOURCE CENTER (VARC)

VARC is a program of VCU that provides training, individual case consultation and information to families and professionals working with individuals with autism in Virginia.

(877) 667-7771 • www.varc.org

AUTISM CENTER FOR EXCELLENCE - VIRGINIA COMMONWEALTH UNIVERSITY

ACE is working to build state-wide capacity to improve outcomes of individuals with ASD by improving the knowledge, skills and understanding of families, educators and professionals who support someone with a spectrum disorder.

(855) 711-6987 • www.vcuautismcenter.org

Brain Injury

BRAIN INJURY ASSOCIATION OF VIRGINIA

Provides current, practical information for professionals, persons with brain injury and family members.

(800) 444-6443 • www.biav.net

Cerebral Palsy

UNITED CEREBRAL PALSYP

UCP is the leading source of information on cerebral palsy and is a leader in advocating for the rights of persons with disabilities.

(800) 872-5827 • www.ucp.org

Chromosome Disorders

CHROMOSOME DELETION OUTREACH

Provides support to parents of children born with rare chromosome disorders. Provides information and promotes research and community understanding of these disorders.

(561) 395-4252 • www.chromodisorder.org

Cystic Fibrosis

CYSTIC FIBROSIS FOUNDATION (CFF)

The Foundation's mission is to assure the cure and control of cystic fibrosis, and to improve the quality of life for those with the disease. The CFF provides education, information, supports specialty care centers, funds research and operates a specialty pharmacy.

(800) 344-4823 • (804) 527-1500 • www.cff.org

Down Syndrome

NATIONAL DOWN SYNDROME SOCIETY (NDSS)

The mission of the NDSS is to benefit people with Down syndrome and their families through education, research and advocacy. Through NDSS, you can locate regional Down Syndrome Associations in Virginia.

(800) 221-4602 • www.ndss.org

More Disability-Specific Organizations

Epilepsy

EPILEPSY FOUNDATION OF VIRGINIA (EFVA)

Promotes awareness about epilepsy, provides assistance to those with the disorder, and provides training for professionals and families.

(800) 332-1000 • (434) 924-8669 • www.efva.org

Fragile X

NATIONAL FRAGILE X ASSOCIATION

Supports research aimed at treatment for Fragile X Syndrome.

(800) 688-8765 • (978) 462-1866 • www.fraxa.org

Hearing Impairments

A. GRAHAM BELL ASSOCIATION

AG Bell promotes its mission: Advocating Independence through Listening and Talking!

(202) 337-5220 • www.agbell.org

Intellectual & Developmental Disabilities

THE ARC OF VIRGINIA

Advocates to focus attention on the needs of individuals who have intellectual and related developmental disabilities

(804) 649-8481 • www.arcofva.org

VIRGINIA ASSOCIATION OF CENTERS FOR INDEPENDENT LIVING (VACIL)

Through its network of sixteen CILs, VACIL advocates for the integration and inclusion of people with disabilities into all aspects of society.

(540) 342-1231 • www.vacil.org

Learning Disabilities

LEARNING DISABILITIES ASSOCIATION OF VIRGINIA (LDA)

LDA Focuses on enhancing educational and vocational services for individuals with learning disabilities who live in Virginia.

(804) 745-9325 • www.ldavirginia.org

Mental Health

MENTAL HEALTH AMERICA, VIRGINIA (MHAV)

MHAV educates the public about mental health and mental illness to eliminate the stigma which prevents people from receiving the help they need.

(804) 257-5591 • www.mhav.org

Spina Bifida

SPINA BIFIDA ASSOCIATION OF AMERICA (SBAA)

The SBAA serves adults and children who live with the birth defect of spina bifida. The association uses education, advocacy, research and service to promote the prevention of spina bifida and enhance the lives of all affected. Contact SBAA for information on regional Spina Bifida Associations in the Roanoke Valley and Hampton Roads areas.

(800) 621-3141 • (202) 944-3285 • www.sbaa.org

Visual Impairments

AMERICAN FOUNDATION FOR THE BLIND (AFB) – SOUTHEAST

(800) 232-5463 • www.afb.org

NATIONAL FEDERATION FOR THE BLIND (NFB)

Both AFB and NFB advocate to ensure that people who are blind or visually impaired enjoy the same rights and opportunities as other citizens.

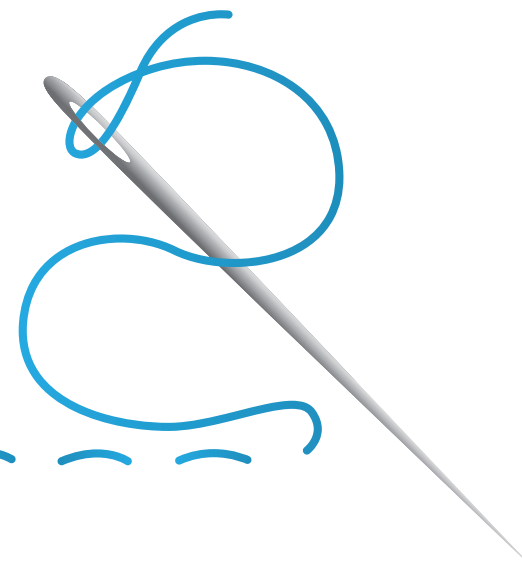
(410) 659-9314 • www.nfb.org



“ Because my daughter was involved with so many professionals, I found it really helpful to have a place to keep basic information about her that I could easily find and copy every time I went to an appointment. ”

Chapter 10

SAMPLE LETTERS & FORMS FOR ADVOCATING FOR YOUR CHILD



Sample Letter 1 - Medically Necessary

February 1, 2011

VIA CERTIFIED U.S. MAIL with RETURN RECEIPT

HEALTH PLAN ADMINISTRATOR - ABC HEALTH

123 Main Street • Anytown, Virginia 23230

Re: Joe Smith, Member No. 225-555-1111

I was recently denied coverage by ABC Health for treatment of my son's cleft palate on the grounds that surgery to repair the cleft palate is considered cosmetic and not medically necessary. I would like to appeal this decision, as is my option under my policy with ABC Health.

Please provide me with a written explanation of the medical reasons ABC Health feels surgery to repair a cleft palate is not considered "medically necessary."

In addition, please include the section of my policy that ABC Health is relying on to make the decision. Finally, I would also like to know the medical background and experience of those involved in making the decision to deny my son's treatment.

I have included for your review, an opinion from Dr. Wow, a nationally renowned specialist in pediatrics, expressing the view that surgery to repair a cleft palate is in fact medically necessary.

Your prompt response is expected and appreciated. I can be reached at (804) 222-1111 if you would like to discuss this letter.

Sincerely,

John Smith

111 American Ave. • Somewhere, VA 23222

Sample Letter 2 - Complaint

February 4, 2011

VIA CERTIFIED U.S. MAIL with RETURN RECEIPT

VIRGINIA BUREAU OF INSURANCE

1300 E. Main Street • Richmond, Virginia 23219

Re: ABC Health

I would like to file a complaint against ABC Health relating to its failure to pay a claim for my daughter's speech therapy.

ABC Health denied coverage for my daughter's speech therapy on two grounds: first, because it said my daughter's school is responsible for covering such therapy; and second, that such therapy is not "medically necessary" and therefore not covered. Unfortunately, my daughter's school only offers limited services under her individual education program. And ABC Health's claim that such therapy is not medically necessary does not appear to be valid since they paid for the therapy for a period of three months before stopping coverage. In addition, the doctor who treated my daughter said that without therapy, my daughter has no chance to develop a normal speech pattern necessary to communicate medical needs by the time she reaches adulthood.

When I told ABC Health that I wanted to appeal their decision to deny coverage, they responded that I could not appeal and that their decision was final. This clearly goes against the language in the health plan I have with ABC Health, which outlines the procedures for a formal appeal.

I need your assistance in resolving this matter and appreciate any assistance you can offer. If you need any additional information, please let me know. I can be reached at (804) 111-6789.

Sincerely,

Mary Doe

123 Main Street • Hometown, VA 23232

Sample Letter 3 - C.O.B.R.A.

February 1, 2011

VIA CERTIFIED U.S. MAIL with RETURN RECEIPT

HEALTH PLAN ADMINISTRATOR - ABC HEALTH

123 Main Street • Anytown, Virginia 23230

Re: John Smith, Member No. 225-555-5555

On December 20, 2010, my employment with CarMin was terminated. I am writing to inform you that I wish to continue coverage for myself and my family from ABC Health through my employer's group health plan.

Please respond to my request in writing, confirming that I have the right to elect COBRA coverage and whether there will be any change in the premium amount I currently pay. I can be reached at (804) 222-1111 if you have any questions.

Sincerely,

John Smith

111 American Ave. • Somewhere, VA 23222

Sample Release of Information Form

Date: _____

Dear _____:

I, _____, the parent/legal guardian of,

_____ (Child's Name),

whose birth date is _____ (Child's Date of Birth),

am requesting copies of medical records/school records from

_____ (School, Physician, or Hospital name)

for the following dates: _____

Please mail this information to the following address:

Signed:

Parent/Legal Guardian

Date

Birth History

Child's Name: _____ Date of Birth: _____ Birthweight: _____ Length: _____

Child's order of birth (first child, second child, etc.): _____

Doctor/Obstetrician: _____ Telephone: _____

Address: _____

How many months pregnant were you when you first saw a doctor? _____ How many times did you see the doctor during your pregnancy? _____

Name of hospital where child was born: _____ Telephone: _____

Address: _____

Child was in the hospital from _____ to _____
(date) (date)

Name of child's primary doctor: _____ Telephone: _____

Name of child's specialty doctor(s): _____ Telephone: _____

Telephone: _____

Telephone: _____

Drugs/medication taken by mother during pregnancy: _____

Mother's illnesses during pregnancy: _____

Was baby full term (9 months)? _____ Yes _____ No If no, weeks of gestation _____ Length of labor: _____

Type of delivery: _____ Normal _____ Breech _____ Precipitate (sudden) _____ Caesarean

Child's condition/problems at birth: _____

Family History

Child's Name: _____)

Does anyone else in the family have a similar condition to the child? _____ Yes _____ No If yes, what is their relationship to child _____)

Do any relatives or members of your immediate family have the following condition? If so, list their relationship to child.)

- Diabetes _____)
- Heart Problems _____)
- Hearing Impairment _____)
- Allergies/Asthma _____)
- Vision Impairment _____)
- Seizure Disorder _____)
- Cerebral Palsy _____)
- Mental Retardation _____)
- Cleft Palate _____)
- Birth Defects _____)

Feeding History

When your baby came home from the hospital, what type of food did he or she eat?

_____ Breast Milk _____ Regular Formula _____ Special Formula _____ Other
(Please Specify: _____)

If your baby's feeding habits changed, what was the change and why?

_____ Breast to Bottle Child's Age _____ Why Change? _____

_____ Formula Change Child's Age _____ Why Change? _____

Changed To: _____

_____ Bottle to Cup Child's Age _____ Why Change? _____

_____ Started Solid Food Child's Age _____ Why Change? _____

_____ Other Changes _____

How long does it take your child to take a bottle or eat a meal? _____

How much does he or she eat? _____

Are there any problems with eating (vomiting, choking, refusing to eat, diarrhea, etc.)? _____

What are your child's favorite foods? _____

What food does your child hate to eat? _____

My Health Passport

If you are a health care professional who will be helping me,

Please Read This

before you try to help me with my care or treatment.

My full name is: _____

I like to be called: _____

Date of birth: _____

My primary care physician: _____

Physician's phone number: _____

This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My Signature: _____

Date Completed: _____

You Can Talk To This Person About My Health: _____

Phone Number: _____

Relationship: _____

I COMMUNICATE USING:

(e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

MY BRIEF MEDICAL HISTORY:

(Include other conditions (e.g. visual impairment, hearing impairment, diabetes, epilepsy) past operations, illnesses and other medical issues)

MY CURRENT MEDICATIONS ARE:

WHEN I TAKE MY MEDICATION, I PREFER TO TAKE IT:

(e.g. with water; with food)

I AM ALLERGIC TO:

(List medications or foods (e.g. penicillin, peanuts))

IF I AM IN PAIN, I SHOW IT BY:

(Also note if I have a low or high pain tolerance.)

My Health Passport (Continued)

IF I GET UPSET OR DISTRESSED,
THE BEST WAY YOU CAN HELP IS BY:

(e.g. play my favorite music)

HOW I COPE WITH MEDICAL PROCEDURES:

(e.g. how I usually react to injections, IVs, physical examinations, x-rays,
oxygen therapy — also note procedures never experienced before or in recent years)

MY MOBILITY NEEDS ARE:

(e.g. whether I can transfer independently, devices I use, pressure relief needed)

WHEN GETTING WASHED & DRESSED, YOU MAY ASSIST ME BY:

THINGS I LIKE TO DO THAT WILL HELP PASS THE TIME:

WHEN DRINKING, YOU MAY ASSIST ME BY:

WHEN EATING, YOU MAY ASSIST ME BY:

MY FAVORITE FOODS & DRINKS ARE:

I DO NOT LIKE TO EAT OR DRINK THE FOLLOWING:

I AM VERY SENSITIVE TO:

(Specific sights, sounds, odors, textures/fabric, etc. that I really dislike, (e.g. fluorescent lights, thunderstorms, bleach, air freshener))

HOW TO MAKE FUTURE/FOLLOW-UP APPOINTMENTS
EASIER FOR ME:

(e.g. give me the first/last appointment of the day, allow extra time for the appointment,
let me visit before my appointment, give information to my caregiver, etc.)

Mi Pasaporte de Salud

Si usted es el profesional médico que me estará ayudando,

Por Favor Lea Esto
antes de ayudarme con mi cuidado o tratamiento.

Mi nombre es: _____

Me gusta que me llamen: _____

Fecha de nacimiento: _____

Mi medico de cabecera es: _____

Número de teléfono de mi doctor: _____

Este pasaporte tiene información muy importante para que me pueda brindar mejor apoyo durante mi estadía en su hospital o clínica. Por favor mantenga este documento con mis otras notas médicas, y donde sea fácil de referenciar.

Mi firma: _____

Fecha: _____

Puedes hablar con esta persona sobre mi salud: _____

Número de teléfono: _____

Relación: _____

YO ME COMUNICO USANDO:

E.j. el habla, idioma preferido, lenguaje de seña, aparatos o asistentes de comunicación, sonidos no verbales. También exprese si tiempo o apoyo adicional es necesitado.

MI BREVE HISTORIAL MÉDICO:

(e.j. Incluya otras condiciones (e.j. discapacidad visual o auditiva, diabetes, epilepsia), operaciones, enfermedades, y otros problemas médicos)

MIS MEDICAMENTOS ACTUALES SON:

CUANDO TOMO MI MEDICAMENTO, PREFIERO TOMARLO:

(e.j. con agua, con comida)

SOY ALÉRGICO(A) A:

(liste medicamentos o comidas, (e.j. penicilina, maní))

SI ALGO ME DUELE, LO MUESTRO:

(También anote si tiene una alta o baja tolerancia al dolor)

Mi Pasaporte de Salud (Continuación)

SI ESTOY MOLESTO O ANGUSTIADO, LA MEJOR FORMA DE AYUDARME ES:

(e.j. tocando mi música favorita)

COMO ENFRENTO A LOS PROCEDIMIENTOS MÉDICOS:

(e.j. como reacciono a inyecciones, inyección intravenosa (IV), exámenes físicos, radiografías, terapia de oxígeno. También anote procedimientos que no ha tenido en recientemente)

MIS NECESIDADES DE MOVILIDAD SON:

(e.j. si puedo moverme independientemente, aparatos que uso, alivio de presión necesario)

CUANDO ME BAÑO Y ME VISTO, ME PUEDE AYUDAR ASÍ:

COSAS QUE ME GUSTAN HACER PARA AYUDAR PASAR EL TIEMPO:

CUANDO ESTOY BEBIENDO, ME PUEDE AYUDAR ASÍ:

CUANDO ESTOY COMIENDO, ME PUEDE AYUDAR ASÍ:

MIS COMIDAS Y BEBIDAS FAVORITAS SON:

NO ME GUSTA COMER O BEBER LO SIGUIENTE:

TENGO SENSITIVIDAD A:

(Imágenes específicas, sonidos, olores, texturas o telas, que no me gusten. (e.j. luces florecientes, tormentas, blanqueador, odorizantes))

COMO HACER CITAS FUTURAS/DE SEGUIMIENTO MÁS FÁCILES PARA MÍ:

(e.j. deme la primera o última cita del día, dedique más tiempo para la cita, déjeme visitar el local antes de mi cita, provea información a mi proveedor de cuidado)

Emergency Information Form for Children with Special Needs

FORMULARIO PARA EMERGENCIAS PARA NIÑOS CON NECESIDADES ESPECIALES

Date Form Completed / Fecha que se completo: _____

By Whom / Por quién: _____

Name / Nombre: _____

Birth Date / Fecha de nacimiento: _____

Nickname / Sobrenombre: _____

Home Address / Domicilio: _____

Home/Work Phone / Teléfono de casa y trabajo: _____

Parent or Guardian / Padre o Tutor legal: _____

Signature for Consent* / Firma de consentimiento*: _____

Preferred Language / Idioma preferido: _____

Emergency Contact Names, Relationship, Phone Number(s) / Nombres en caso de emergencia, parentesco, número(s) de teléfono: _____

Physician or Provider Signature / Firma del Doctor o Proveedor

Print Name / Nombre (letra de molde)

PHYSICIANS / MÉDICOS:

Primary Care Physician / Médico principal:

Emergency Phone / Número de teléfono de emergencia:

Fax: _____

Current Specialty Physician / Médico especialista actual:

Specialty / Especialista en: _____

Emergency Phone / Número de teléfono de emergencia:

Fax: _____

Current Specialty Physician / Médico especialista actual:

Specialty / Especialista en: _____

Emergency Phone / Número de teléfono de emergencia:

Fax: _____

Preferred Emergency Room / La sala de emergencia de su preferencia:

Pharmacy & Phone Number / Farmacia y Número de teléfono:

Anticipated Tertiary Care Center (Hospital with highest level of care) / Hospital con un alto nivel de cuidado: _____

*Consent to share this form with health care providers / Consentimiento para compartir esta forma con proveedores de cuidado de salud

**DIAGNOSES, PAST PROCEDURES & PHYSICAL EXAM /
DIAGNÓSTICOS, PROCEDIMIENTOS ANTERIORES Y EXÁMEN FÍSICO:**

1. _____
2. _____
3. _____
4. _____

Baseline physical findings / Resultados de análisis básicos: _____

Baseline vital signs / Signos vitales básicos: _____

Medications / Medicamentos:

1. _____
2. _____
3. _____
4. _____
5. _____

Significant baseline ancillary findings (lab, x-ray, ECG) / Resultados básicos de condición secundaria (Laboratorio, rayos x, y ECG): _____

Medical equipment & supplies / Equipo médico y materiales _____

MANAGEMENT DATA / INFORMACIÓN ADMINISTRADA:

Allergies: Medications/Foods to be avoided: _____ and why:
Alergias: Medicamentos y comidas que deben que evitar: _____ y la razón:

1. _____
2. _____
3. _____

Procedures to be avoided: _____ and why:
Procedimientos que deben evitar: _____ y la razón:

1. _____
2. _____
3. _____

IMMUNIZATION DATES / FECHAS DE VACUNAS

DPT / difteria, tétano, pertussis _____

OPV / antipoliomielítica oral _____

MMR / triple vírica _____

HIB / H. influenza tipo B _____

Hepatitis B _____

Varicella / Varicela _____

TB status / Resultado de la prueba de tuberculosis _____

Other / Otra _____

ANTIBIOTIC PROPHYLAXIS / PREVENCIÓN CON ANTIBIÓTICOS

My child [needs / does not need] antibiotic prophylaxis (prevention with antibiotics).
(circle one)

Mi niño/niña [necesita / no necesita] prevención con antibióticos.
(circule uno)

Indication (diagnosis needing antibiotic prevention) / Indicación (diagnóstico que necesita tratamiento preventivo con antibióticos): _____

Medications and doses / Medicamentos y dosis: _____

COMMON PRESENTING PROBLEMS / PROBLEMA COMUNES

Problem / Problema	Suggested Diagnostic Studies / Estudios Diagnósticos Sugeridos	Treatment Considerations / Tratamiento Considerado
-----------------------	---	---

_____	_____	_____
_____	_____	_____
_____	_____	_____

Comments about child, family, or other specific medical issues / Comentarios sobre el niño/niña, la familia, u otras condiciones médicas específicas: _____

Your Child's Relationship Map

FAMILY

Examples: Parents, Siblings & Extended Family

COMMUNITY

Examples: Places of Worship & Local Shops

PAID RELATIONSHIPS

Examples: Home Supporters & Day Services

NON-PAID RELATIONSHIPS

Examples: Friends & Neighbors

Now that You are Eighteen

YOUNG ADULT TRANSITION PLAN WORKSHEET

HEALTH

	THINGS I NEED TO KNOW OR DO	WILL SOMEONE ELSE HAVE HELP ME WITH THIS?	I WILL FINISH BY (DATE)	DONE
I SIGN MY OWN RELEASE OF INFORMATION FORMS OR HAVE A PLAN IN PLACE FOR GUARDIAN OR HEALTHCARE SURROGATE.	Yes / No	Yes / No		
I MAKE MY OWN MEDICAL DECISIONS OR HAVE OTHER ARRANGEMENTS IN PLACE.	Yes / No	Yes / No		
I HAVE TRANSITIONED TO AN ADULT HEALTHCARE PROVIDER OR KNOW THAT MY CURRENT PHYSICIAN CAN CONTINUE SEEING ME.	Yes / No	Yes / No		
I HAVE BEEN REFERRED TO ADULT SPECIALTY PHYSICIANS AND HAVE MADE INITIAL APPOINTMENTS TO ESTABLISH CARE WITH THEM.	Yes / No	Yes / No		
IF I AM NO LONGER ELIGIBLE FOR MEDICAL CARE UNDER MY FAMILY'S INSURANCE, I HAVE LOOKED AT MY OPTIONS AND APPLIED FOR OTHER FUNDING SOURCES.	Yes / No	Yes / No		
I AM AWARE OF SUPPORT GROUPS IN MY AREA TO SUPPLEMENT FAMILY SUPPORT.	Yes / No	Yes / No		
I HAVE A MEDICAL HISTORY SUMMARY THAT I CARRY AND THAT CAN BE GIVEN TO MY NEW DOCTORS.	Yes / No	Yes / No		
I MANAGE MY SCHEDULE OF MEDICAL APPOINTMENTS AND MAKE ARRANGEMENTS FOR TRANSPORTATION TO ATTEND, IF NEEDED.	Yes / No	Yes / No		
I KNOW WHAT TO DO FOR MINOR AILMENTS, LIKE A COLD, AND HEALTH EMERGENCIES.	Yes / No	Yes / No		
I HAVE CHOSEN A PHARMACY WHERE MY CURRENT AND NEW PRESCRIPTIONS CAN BE FILLED.	Yes / No	Yes / No		

INDEPENDENT LIVING

	THINGS I NEED TO KNOW OR DO	WILL SOMEONE ELSE HAVE HELP ME WITH THIS?	I WILL FINISH BY (DATE)	DONE
I HAVE PLANS FOR AFTER HIGH SCHOOL.	Yes / No	Yes / No		
I CAN TAKE CARE OF MY PERSONAL NEEDS OR HAVE IDENTIFIED SOMEONE TO HELP.	Yes / No	Yes / No		
I HAVE PLANS FOR INDEPENDENT LIVING, HOUSING AND TRANSPORTATION.	Yes / No	Yes / No		
I KNOW HOW TO MANAGE MONEY AND BUDGET HOUSEHOLD EXPENSES.	Yes / No	Yes / No		
I KNOW WHAT TO DO TO ENROLL IN SCHOOL OR TRAINING OR TO APPLY FOR WORK.	Yes / No	Yes / No		
I KNOW HOW TO GET ANY ACCOMMODATIONS I NEED FOR WORK OR SCHOOL.	Yes / No	Yes / No		
I HAVE A DRIVER'S LICENCE OR STATE IDENTIFICATION.	Yes / No	Yes / No		



**CENTER FOR
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