

Health Care Financing for Your Child with Special Needs: Six Ways to Access Medicaid & Other Health Care Benefits



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## **Contents**

	Managing Health Care for Children with Special Needs	
	Basics of Health Care Financing	4
	Medical Home	4
	The Family Role in Health Care for Children with Special Needs	5
	Public Programs for Children with Special Needs	7
	Children with Special Health Needs Program (CSHN)	7
	Medicaid and the State Children's Health Insurance (SCHIP) Program	
	Schools and the Individuals with Disabilities in Education Act (IDEA)	8
	Medicare	9
	Supplemental Security Income (SSI)	9
	Six Ways to Access Medicaid	11
	Way #1: Dr. Dynasaur	12
	Way #2: Reach Up	14
	Way #3: Katie Beckett	15
	Way #4: Home and Community-Based Waivers	16
	Way #5: Supplemental Security Income (SSI)	
	Way #6: Categorical Need (Other Special Circumstances)	19
Л	Benefits of Medicaid and EPSDT	
	Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Services	
	Medicaid Benefits and Programs for Children with Significant Disabilities or Chronic Conditions	
	Challenges and Limitations on Benefits in Medicaid	
	Coordination of Benefits	25
	Advocating for Eligibility or Benefits for Your Child	
	General Suggestions	
	Advocating for Katie Beckett	
	Advocating for Supplemental Security Income (SSI)	
	Advocating for School Services	
	If You Feel Your Child's Needs are Not Being Met	31
	Grievance and Appeals	
	What is a Grievance or Appeal?	
	Internal Medicaid Grievance and Appeals Options.	
	Help with Grievance and Appeals Process	35
7	Transition to Adulthood for Children with Special Needs	
	Health Insurance Coverage at Age 18	
	School Services	
	Medicaid Eligibility Based on Income for Young Adults	
	Other Vermont Health Insurance Programs Based on Income for Young Adults	
	Medicaid Access Based on Disability for Young Adults	
	Medicare	
	Medicare/Medicaid Dual Eligibility	40
	Appendix A: Glossary	
	Appendix B: Acronyms	
	Appendix C: Useful Resources and Contact Information	46

## Introduction and Tips on How to Use this Booklet

Between 13% and 16% of children in the United States are estimated to have a special health care need. The Maternal and Child Health Bureau (MCHB) defines children with special health care needs as those who "have or are at elevated risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount not usually required by children."

Children with special needs use more health care and rehabilitative services than typically developing children. They often require services from medical specialists; physical, speech or occupational therapists; developmental service or mental health providers; and/or home health care providers.

Many families connected to Vermont Family Network spend a great deal of time trying to understand how to provide and pay for treatments, therapies, care, supplies, and medical equipment for their children. In Vermont, 21% of families report experiencing financial problems as a result of a child's health needs. Over 30% of Vermont families report that a child's health needs caused a family member to cut hours or stop working all together.

We have written this booklet as a guide for families seeking information about health care financing for children with special health care needs. We hope it will help you navigate the complicated mix of private and public health programs.

Medicaid provides a comprehensive benefit package for children and includes services that are not usually covered by private health plans, so we emphasized Medicaid eligibility and Early Periodic, Screening, Diagnosis and Treatment (EPSDT) benefits. We have also included information on advocacy, the grievance and appeals process for Medicaid and private insurance, and transitional coverage for youth from 18 to 21 years.

This information is complex. Not all of it will be of interest or relevance to everyone. You may want to scan the Table of Contents to see which chapters might be most useful to your child and your family situation before (or instead of) attempting to read the booklet cover-to-cover.

A lot of technical terms and phrases are used in the world of health care and health care financing. To help you become more familiar with the "jargon", we have typed these words in italics the first time we use them. A glossary, a list of acronyms, and other resources are included at the back of this booklet.

The information in this booklet (especially phone numbers, websites, addresses, and dollar figures) can change frequently. Between printings, please check the Vermont Family Network website or contact us for the most up-to-date information available.



Vermont Family Network is a non-profit organization that promotes better health, education, and well-being for all children and families, with a focus on children and young adults with special needs. We are here to provide support, information, and assistance to families and children and the professionals in their lives. We produced this booklet and can answer questions about health care financing or other health or school concerns related to your child. Please contact us at 1-800-800-4005 or 802-876-5315. You can also check out our website at www.VermontFamilyNetwork.org.



# Managing Health Care for Children with Special Needs

Our health care system is difficult to navigate and access, especially for children with special health care needs. Three factors make a real difference to families in supporting their children to get the medical care they need.

First, families need to be able to pay for health care. For most families, that means they must have access to good *medical insurance*. Health insurance plans and health care services can be private or public. Many families of children with special health care needs rely on a mixture of both. However, many families remain unaware that their child could be eligible for public health insurance programs regardless of family income. If you have a child with significant needs, you should consider applying for Medicaid.

Second, children with special health care needs benefit greatly

if they have a *medical home*. In a medical home, a primary physician focuses on the needs of the patient (and family) and coordinates care with all other providers. This is especially important to children with disabilities and chronic conditions who often receive care from multiple providers of specialized health care services.

Finally, children's access to health care improves when families are recognized as the experts on their child with special needs and are able to inform and work with professionals and caregivers to determine the treatment, care, and supports their child and family needs. Access to public health care benefits may also be increased through family use of a **special needs trust**, which is a mechanism to help individuals with disabilities and chronic conditions access benefits while allowing for financial aid and care from their families.

This chapter provides basic information on health insurance, the medical home, and the family role in health care that you might find useful to ensure your child has access to the health care he or she needs.

provides information about the types and characteristics of different public and private health insurance plans. This booklet can be obtained at Vermont Family Network or at BISHCA or found online at: www.bishca.state.vt.us/sites/default/files/consumer-guide-health-Ins.pdf.

#### **Basics of Health Care Financing**

In the United States, some families and individuals access health insurance through their employer(s). Others buy health insurance on their own, rely on government sponsored programs, or go without insurance.

Many organizations offer insurance. Some are private *for-profit* companies such as CIGNA and AETNA. Private *non-profit* companies in Vermont include Blue Cross/Blue Shield and Mohawk Valley Physicians Health Plan (MVP). Government sponsored plans include Tri-Care (for military personnel and their families), Medicare (for elders and people with disabilities), and Medicaid (for children and low-income individuals).

Plans take many forms and the terminology can be very confusing. The cost of insurance can vary widely from plan to plan. Some plans require a monthly premium to receive coverage. Some have additional cost sharing in the form of *deductibles* and/or *co-payments* (*co-pays*).

Some plans offer comprehensive benefits, but some offer only *catastrophic* or very *high deductible* coverage after you have spent thousands of dollars out-of-pocket. Some plans offer benefits that are very broad, while others may have *exclusions* or not cover *pre-existing conditions*.

Some plans like *health savings accounts (HSAs)*, are basically tax-sheltered savings accounts funded by individuals and/or their employer. Other plans, like *health maintenance organizations (HMOs)* and *preferred provider organizations (PPOs)* may offer care only through providers affiliated with the organization or require a higher co-pay or *deductible* for provider services outside the network.

*Indemnity plans* pay for all or a portion of the care the insured receives. These may have different rates of reimbursement for in-network vs. out-of-network providers. Indemnity plans often split costs between the insurer (usually 80%) and the insured (usually 20%).

For more detailed information on health care financing (especially explanations of terms and forms of private insurance), we recommend reading *A Consumers Guide to Health Insurance* by the Vermont Department of Banking, Insurance, Securities & Health Care Administration (BISHCA). The *Consumer's Guide* 

#### **HEALTH CARE REFORM**

The Affordable Care Act (ACA) passed by Congress in 2010 will change health care financing options available to individuals and families over the next several years. The ACA requires the gradual development of new government sponsored insurance options for people who would otherwise have difficulty finding or paying for it. It also requires private insurance companies to cover children up to age 26 on their parents' policies and prohibits denying or limiting coverage for children due to pre-existing conditions.

In 2011, Vermont passed a law to move the state toward a universal and unified system of health care financing by 2017. This law incorporates some of the steps required of states by the ACA and may move the state toward a *single payor* health care administration system.

Both the federal Affordable Care Act and Vermont's reform efforts will undoubtedly change the options available to all citizens in the coming years.

#### **Medical Home**

Every child deserves quality medical care and a *medical home*. The term medical home describes an approach to medical care that is family centered, collaborative, and inclusive of all the aspects of a patient's life and care. Establishing a medical home is especially important for children with special health care needs to assist in the coordination of what may be a complex mix of private insurers and providers and public programs.

A medical home is not a building, house, or hospital. It's an approach to providing health care services in a high quality and cost effective manner. It is about partnerships and how your child is cared for. Medical homes are a new way of thinking about health care for your child. They do not happen right away – they take time to build and develop. Medical homes don't all look alike. Together, you and your child's doctor create a medical home that works best for your child.

In a medical home, you have a doctor who helps you keep your child healthy. When your child gets sick or has other issues, the doctor and staff may suggest to you that other professionals

should be included on your child's health care team. Care is focused around the whole child. It is like a puzzle, where all pieces must be looked at to see the entire picture. Finally, a medical home accepts your type of insurance, including Medicaid.

You and your child's doctor can use the following checklist to begin to build a strong medical home for your child.

#### MEDICAL HOME CHECKLIST

- You are valued and treated as the person who knows your child best. You are the most important person on your child's health care team.
- Your family's culture and religious beliefs are respected.
- Your preferences for treatment and care are honored.
- You and your child's doctor share respect and trust. Your doctor partners with you, your child and others, to meet your child's medical needs.
- Your child receives his/her immunizations, well-child visits child development checks, and urgent care when needed.
- Your doctor makes sure you understand the medical condition or diagnosis and what choices there are for
- Your child's doctor provides helpful information to you and other members of the care team. He/she helps to manage your child's care.
- · You get help finding specialty care or other services when needed.
- If your child gets sick or has special health care needs, you feel supported. You are given information about ongoing health concerns.
- Your doctor allows all the time you and your child need for the appointment or is willing to schedule a follow up appointment.
- Your child's doctor connects you to support organizations for community resources, health care financing questions, and parent to parent support.

#### The Family Role in Health Care for **Children with Special Needs**

Beyond arranging for health care financing and developing a medical home, families of children with special needs may find themselves in other demanding roles. Parents and siblings may need to work especially hard to establish and maintain relationships with the many people on whom the child with special needs might depend, and to support the child in developing social relationships.

Families may want to help their child develop a *Circle of* **Support**. A Circle of Support "is a group of people who care about change happening for the focus person and choose to give their time and resources working for change. They see themselves as an action oriented group that exists with and for the person, commit themselves to working alongside the focus person, and meet from time to time for as long as it takes to assure that the person has a secure and interesting community life." (Beth Mount, 2002) For more information on how to build a Circle of Support for your child, contact Vermont Family Network.

Families may also find themselves in advocacy roles that require seeking out or developing financial and/or legal expertise. For example, families may want to consider the use of a special needs trust (SNT) to help their child become eligible for Medicaid and Supplemental Security Income (SSI) without the family having to "spend down" the family's assets.

With legal expertise or advice (there are lawyers who specialize in this area), families can establish and fund a self-settled **special needs trust**. The trust beneficiary would be the individual with the disability and the trust would be managed by trustees, often the parents of the individual. The trustees can make a wide range of purchases for the individual using the trust funds, which are often placed in bank accounts in the name of the trust. The advantage of this arrangement is that these trust funds would not be counted as resources for purposes of qualifying for Medicaid.

Special needs trusts which are funded by the individual's own money (inheritance, court settlement, accumulated Supplemental Security Income checks, etc) can only be placed in a self-settled trust with a **payback** provision. Any funds left in this trust at the time of death of the individual with a disability must first be paid back to the state for Medicaid expenses.

Another type of special needs trust is funded with assets that do not belong to the individual with a disability. Parents may wish to leave assets for their child with a disability through their wills or via life insurance or through contributions from other family members. By steering these assets directly to the trust rather than to the individual, parents can avoid jeopardizing vital government benefits while still providing their son or daughter with a good quality of life. Unlike the self-settled special needs trust, a *third party special needs trust* does not have a payback provision at the time of the death of the individual with the disability. This would allow parents to name other beneficiaries, such as siblings of the disabled child, as successor beneficiaries. Chapters 3 and 4 will discuss the benefits of Medicaid that a special needs trust might enable a child to receive.

#### **Summary**

Families often report that arranging care for their child with special needs feels like a full-time job. In addition to developing expertise on health care and financing, families may need skills in legal advocacy and knowledge of laws, regulations, and policy. Hopefully this booklet will help. See Chapter 5 for tips on how to advocate for your child and Chapter 6 on grievance and appeals processes.

Please contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org if you want more information or support about these topics.



# **Public Programs for Children with Special Needs**

Federal and state laws have created several programs to provide services or assist with health care for children with special needs.

This chapter will give some basic information about these programs, including:

- Children with Special Health Needs Program
- Medicaid and the State Children's Health Insurance Program (SCHIP)
- Individuals with Disabilities in Education Act (IDEA)
- Medicare
- Social Security Supplemental Security Income (SSI)

## **Children with Special Health Needs Program**

(Title V of The Maternal and Child Health Block Grant)

The federal Maternal and Child Health program to improve the health of women and children began in 1935. In Vermont today, it helps support Vermont's Children with Special Health Needs Program (CSHN) to provide a range of services to children, birth to age 21, who have complex health conditions.

Housed in the Vermont Department of Health, this program provides information and resources to help families support their children's well being, growth, and development. The CSHN Child Development Clinic offers developmental evaluation,

follow up, and referral to community services to children, generally under age eight, who may have a developmental delay or disability. Clinic services are provided in Burlington and other sites statewide.

CSHN may also provide family supports (including respite, care coordination, and limited financial assistance) and specialty clinic services to children with a wide range of conditions or diagnoses. These services are provided by CSHN clinical staff, as well as community-based partners across the state. A child's eligibility for a specific program depends on a number of factors.

CSHN works in close partnership with Vermont's Children's Integrated Services Early Intervention (CIS-EI) program as well as with primary and specialty care providers to ensure that Vermont children and their families benefit from coordinated and comprehensive developmental and health services.

One in four of all children in the United States have health insurance coverage through Medicaid or SCHIP. In Vermont, which has been a national leader in providing health care coverage to citizens, about 45% of children have health insurance coverage from Medicaid and SCHIP. Most Vermont children with significant chronic conditions or disabilities receive coverage through Medicaid.

Children may be eligible for Medicaid because of their family income, a disability, or other special situations. Families with access to private health insurance may find that Medicaid can be used to reduce out-of-pocket expenses by supplementing private plans, especially for children with special health care needs.

See Chapters 3 and 4 for more detailed information on how to access Medicaid and the benefits it can provide.

#### **Medicaid and the State Children's Health Insurance Program (SCHIP)**

Medicaid was enacted in 1965 as a "safety net" for low-income children and elders and for medically needy families and individuals. The cost is shared by the federal and state governments based on complex formulas that try to measure the level of state need and ability to pay. In every state, the federal government pays at least half of the cost of the program. In some states, but not in Vermont, localities share in the cost as well.

The federal government establishes general guidelines and minimum benefits and eligibility for Medicaid. One of the federal requirements is that Medicaid for children must provide a very comprehensive package of benefits called **EPSDT** (Early Periodic **Screening, Diagnosis, and Treatment)**. Except for EPSDT, states have considerable leeway to determine who is eligible and what types of services recipients can receive. States can exceed the minimum federal requirements.

In general, Vermont provides greater coverage and more generous benefits than most other states. In addition to Medicaid, the federal State Children's Health Insurance Program (sometimes called SCHIP or CHIP) was adopted in 1997 to provide additional funds to states to expand access to health care for children living in families with moderate incomes. Vermont has combined Medicaid and SCHIP funding into a comprehensive children's health insurance program called Dr. Dynasaur.

#### Schools and the Individuals with **Disabilities in Education Act (IDEA)**

Congress enacted a legal foundation for educational supports for children with disabilities in 1975. This law was expanded in the 1990 Individuals with Disabilities in Education Act (IDEA) to assure that all students with disabilities have a right to a free, appropriate education (FAPE). The federal government provides guidelines and some financial assistance to states to support them in providing special educational services, which may include health-related services. The IDEA established several important programs for children with special needs.

#### **EARLY INTERVENTION (PART C)**

PART C of the IDEA is a federal grant program. Under this program, states provide comprehensive, coordinated, multi-disciplinary, interagency early intervention services for infants and toddlers with a developmental delay or at risk for a developmental delay (and their families) from birth to age three.

The federal government provides approximately a third of the funding for this program. Children receiving early intervention will have services planned and coordinated by an *Individual* Family Service Plan (IFSP).

In Vermont, the Part C early intervention program is a part of **Children's Integrated Services (CIS)**. CIS provides an array of services and supports for pregnant women, families, and their young children up to six years of age.

#### **SPECIAL EDUCATION (PART B)**

PART B of the IDEA provides school based special education from age three through 21 (until the 22nd birthday). For children age three to school age in Vermont, these services are called **Essential Early Education (EEE)**. From age six through graduation, the services are referred to as **special education**.

Children receiving EEE services or special education services will have an Individualized Education Program (IEP) written for them. The IEP consists of a written statement for each eligible child with a disability that is developed, reviewed, and revised in accordance with Vermont Special Education Regulations. It includes a statement of the student's present levels of performance and educational placement; a statement of the specific goals and objectives of the special education program; a description of the special education services, related services, and supplementary aids and services that the child will need to be able to benefit from his or her educational program; and accommodations and/or modifications necessary for the child to access the general education curriculum.

#### **SECTION 504**

Section 504 of the Rehabilitation Act of 1973 is a civil rights law designed to eliminate discrimination on the basis of disability in any program or activity receiving federal financial assistance. Section 504 requires the provision of appropriate educational services – services that are designed to meet the individual needs of qualified students to the same extent that the needs of students without a disability are met.

Essentially, Section 504 was designed to "level the playing field" to ensure full participation by individuals with disabilities. Examples of services that can be provided through Section 504 to ensure equal access for all students with diagnosed disabilities include: physical and occupational therapy, counseling services, increased time to complete tests, preferential seating, and assistive technology.

#### **MEDICAID AND THE IDEA**

While schools are legally responsible to provide IDEA-related health services at no cost to eligible students, schools can ask Medicaid to reimburse them for these services. The federal government will allow Medicaid payment for services if:

- · the student is Medicaid eligible;
- the services are included in the student's IEP;
- the services are medically necessary and included in a Medicaid covered service category (speech therapy, physical therapy, etc.);

- all other federal and state Medicaid regulations are followed, including those for provider qualifications, comparability of services, and the amount, duration, and scope of service provisions;
- the services are included in the state's plan or available under EPSDT; and
- the school has written parental consent to bill Medicaid.

The fact that a school bills Medicaid cannot impact a child's eligibility for Medicaid or reduce the availability of coverage for any other medically necessary services through Medicaid. However, parents should be informed about services or equipment that schools obtain through Medicaid for their children to ensure they are in agreement with the purchase of goods or services. Medicaid will have limitations on when and how similar services can be accessed or when the item can be later replaced, so you should be comfortable that the purchase is the correct one for your child.

#### HOME SCHOOLING AND INDEPENDENT SCHOOLS

Children with disabilities enrolled by their parents in independent schools or home study programs have no right to an Individualized Education Program (IEP) or a free appropriate public education (FAPE). When services are provided, they will be at the discretion of the *local education agency (LEA)* in which the independent school or home study program is located. This is usually referred to as an individualized service plan.

Schools are required to locate, identify, and evaluate all independent school and home study children. The evaluation process is comparable to that for other children attending public schools in the supervisory union.

#### Medicare

Medicare is a federal health insurance program for people age 65 and over, people under age 65 who are disabled, and individuals with permanent kidney failure that requires regular dialysis or a kidney transplant. The vast majority of Medicare recipients are seniors and adults with disabilities who have enough of a work history to qualify for Social Security retirement.

A few Vermont children (for example, some with kidney disease or cystic fibrosis) do benefit from this program. In addition, young adults with significant disabilities may be able to access Medicare as they transition into adulthood. (See Chapter 6 for more information on Medicare and transition to adult programs.)

#### **Supplemental Security Income (SSI)**

SSI is a federal program under the Social Security Administration that provides monthly cash benefits to individuals (including children) with disabilities who have limited income and resources. Children and adults who qualify for SSI benefits automatically qualify for Medicaid. (See Chapter 3 for details on SSI eligibility and benefits.)

#### **Summary**

A child with special needs in Vermont might be able to access one, or several, or all of the health or health-related services listed in this chapter. Each has different requirements and different ways to assist in providing health care. For more information you can contact the programs directly or call Vermont Family Network.

Please contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org if you want more information or support about these topics.



# **Eligibility: Six Ways to Access Medicaid**

There are six primary ways that children or families may access Medicaid. Each program has specific rules that determine eligibility, premium costs, and benefits. This chart lists each of the six ways discussed in this chapter, and the primary basis for eligibility:

WAY#	PROGRAM	CRITERIA FOR ELIGIBILITY
1	Dr. Dynasaur	Limited Family Income
2	Reach Up	LimitedFamily Income and Resources; Expenses
3	Katie Beckett	Significant Child Disability and Limited Child Income and Resources
4	Home and Community- Based Waivers	Physical, Developmental, or Mental Health Disability; Traumatic Brain Injury
5	Supplemental Security Income (SSI)	Significant Child Disability and Limited Child Family Income and Resources
6	Categorical Need	Certain Special Circumstances

Two of the ways are based on family income. Dr. Dynasaur is the easiest way for a family to apply and qualify for Medicaid. For most families, this is the first of the six ways to consider for a child with or without special needs. Some families might qualify for Reach Up, a work support program with an added benefit of health care access while parents are in the program.

Children with special needs who do not qualify for Medicaid based on family income, or those who would find Dr. Dynasaur premiums a hardship, may be able to qualify for Medicaid through Katie Beckett, a Home and Community-Based Waiver, or Supplemental Security Income. Special circumstances, such as current or previous foster care, crisis, or financial hardship due to high medical expenses, may also allow a child to qualify for Medicaid. Regardless of which of the six ways a child obtains Medicaid coverage, the child will receive the comprehensive EPSDT benefits that are discussed in Chapter 4.

#### WAY #1: Dr. Dynasaur

#### WHAT IS DR. DYNASAUR?

Dr. Dynasaur is Vermont's children's health insurance program. It is funded through a combination of Medicaid and the State Children's Health Insurance Program. It is the easiest way for a child to access Medicaid, regardless of whether he or she has special needs. A family may have other health insurance coverage and still qualify for Dr. Dynasaur coverage.

#### WHO IS ELIGIBLE FOR DR. DYNASAUR?

Whether a child is eligible for Dr. Dynasaur depends on family income and household size. (A household is defined as the number of related people living in the same house, including unmarried parents with children in common, and any of their children living in the home under age 21.)

Each year, the federal government calculates an income figure, called the *federal poverty level (FPL)*. This amount determines eligibility for a wide range of federal benefits, including Medicaid. In Vermont, all of the children in a family can qualify for Dr. Dynasaur if the family has a total income at or below 300% of the Federal Poverty Level (FPL).

The FPL is not a true indicator of need or poverty. In Vermont, the livable wage (the amount a family needs to access minimal housing, food, and health care) is actually much higher than the artificially calculated federal poverty level or FPL. This is why most Vermont programs use higher percentages of the "poverty" level to determine eligibility. The FPL is re-calculated every January.

In 2011, a family of two qualified for Dr. Dynasaur if the family income was at or below 300% of the FPL, or \$3,713 per month (\$44,556 per year). A family with a household size of four qualified if their income did not exceed \$5,613 per month (\$67,356 per year).

Pregnant women can also qualify for Dr. Dynasaur, but household income limitations are lower (200%FPL) than they are for children. The unborn child counts in the household size, so a woman with no spouse or other children expecting to deliver one child would count as a family of two. Pregnant women expecting multiple births would have a larger household size.

You can use the chart below to see if your family qualifies for Dr. Dynasaur. Eligibility is based on monthly income, but the annual equivalent income is also listed. You may still qualify if your monthly income is higher than the amount listed if you have child care expenses and income from a job or if a member of your household is making court-ordered child support payments.

#### 2011 FEDERAL POVERTY LEVEL INCOME GUIDELINES FOR DR. DYNASAUR

Use to Calculate Your Income as a Percentage of the Federal Poverty Level (FPL)

Number of People in Household	Yearly/Monthly Income at 100% FPL	Yearly/Monthly Income at 150% FPL	Yearly/Monthly Income at 185% FPL	Yearly/Monthly Income at 200% FPL	Yearly/Monthly Income at 225% FPL	Yearly/Monthly Income at 300% FPL
1	\$11,052/\$921	\$16,584/\$1,382	\$20,448/\$1,704	\$22,104/\$1,842	\$24,864/\$2,072	\$33,156/\$2,763
2	\$14,856/\$1,238	\$22,284/\$1,857	\$27,480/\$2,290	\$29,700/\$2,475	\$33,420/\$2,785	\$44,556/\$3,713
3	\$18,660/\$1,555	\$27,984/\$2,332	\$34,512/\$2,876	\$37,308/\$3,109	\$41,964/\$3,497	\$55,956/\$4,663
4	\$22,452/\$1,871	\$33,684/\$2,807	\$41,544/\$3,462	\$44,904/\$3,742	\$50,520/\$4,210	\$67,356/\$5,613
5	\$26,256/\$2,188	\$39,384/\$3,282	\$48,564/\$4,047	\$52,500/\$4,375	\$59,064/\$4,922	\$78,756/\$6,563
6	\$30,060/\$2,505	\$45,084/\$3,757	\$55,596/\$4,633	\$60,108/\$5,009	\$67,620/\$5,635	\$90,156/\$7,513
7	\$33,852/\$2,821	\$50,784/\$4,232	\$62,628/\$5,219	\$67,709/\$5,642	\$76,164/\$6,347	\$101,556/\$8,463
8	\$37,656/\$3,138	\$56,484/\$4,707	\$69,660/\$5,805	\$75,300/\$6,275	\$84,720/\$7,060	\$112,956/\$9,413

You can also use the FPL Income Guidelines chart to see what your family income equals as a percentage of the FPL. This will help you determine the monthly premium your family would be asked to pay, if any. This premium would provide for Dr. Dynasaur coverage for all the children in your family. Please note that these figures change from year to year.

#### WHAT ARE THE PREMIUMS FOR DR. DYNASAUR?

Once you have calculated the FPL amount and percentage that your family income equals from the FPL Income Guidelines chart, you can calculate the monthly premium that your family will be



charged. The monthly premium rate varies depending on family income and whether your family has other insurance. The same premium covers all the children in the family, whether there is one child or several. There are no co-pays or other costs to a family to receive health care under Dr. Dynasaur.

This chart shows the premium that a family must pay to cover all the children in the household. Your premium depends on your family's income and where it falls as a percentage of the FPL.

#### 2011 MONTHLY PREMIUM CHARGE FOR DR. DYNASAUR

Income Level	Monthly Premium
Below 185% FPL	None
185%–225% FPL	\$15/month
225%–300% FPL with other health insurance coverage	\$20/month
225%–300% FPL with no other health insurance coverage	\$60/month

There may be some expenses that could be subtracted from your family income to determine your child's eligibility and the premium you must pay. These expenses are allowable child care costs, child support paid outside of the home, and a work expense deduction of \$90 per month for each person in the home who is working.

The premium for a pregnant woman to enroll in Dr. Dynasaur is between zero and \$15 per month.

#### **HOW DO I APPLY FOR DR. DYNASAUR FOR MY CHILD?**

You can apply for Dr. Dynasaur benefits online at http://dcf.vermont.gov/mybenefits/apply\_for\_benefits.

If you have problems using the online application, call the Benefits Service Center during regular business hours at **1-800-479-6151**. You can also visit your local Department for Children and Families (DCF) Office of Economic Services. They will give you an application and/or help you complete the application.

Vermont Family Network also has Dr. Dynasaur applications that we can help you to fill out, or we can send you the paper application.

#### **WAY #2: Reach Up and Reach First**

#### WHAT IS REACH UP?

Reach Up (called Temporary Assistance for Needy Families or TANF by other states and the federal government) helps low income families with children. Reach Up provides families with case management, cash assistance for basic needs, and support services to help them work toward self-sufficiency.

Families who receive Reach Up are also eligible for health coverage for all the adults and children in the family through Medicaid and state subsidized childcare. They may receive fuel assistance, food stamps, job training, and more.

#### WHO IS ELIGIBLE FOR REACH UP?

Eligibility depends on income, resources, living expenses, family members in the household, and other factors.

#### WHAT IS REACH FIRST AND WHO IS ELIGIBLE?

If a family needs only temporary, short-term help and is likely to be self-sufficient in four months or sooner and meets eligibility requirements, the Reach First Program may be appropriate. Reach First provides access to Medicaid for members of the family as well as supports to reach self-sufficiency.

#### WHAT ARE THE PREMIUMS FOR REACH UP AND REACH FIRST?

There are no premiums for Reach Up or Reach First.

#### **HOW DO I APPLY FOR REACH UP AND REACH FIRST?**

You can apply online at http://dcf.vermont.gov/mybenefits/ apply for benefits or call the Benefits Service Center at 1-800-479-6151 to request a paper application.

Vermont Family Network can assist you in filling out the paper and online application.



#### **WAY #3: Katie Beckett**

#### WHAT IS KATIE BECKETT?

Katie Beckett is a way to grant Medicaid to children with a condition that is significant enough to qualify for institutional care, even if family income is higher than generally allowed for Medicaid. Parent income and resources are not counted to determine eligibility, only the child's income and resources are counted toward eligibility.

This program was named after a child named Katie Beckett who was unable to go home from a hospital until the federal government approved this program. It is formally called Disabled Children's Home Care (DCHC).

Examples of disabilities and conditions that may allow for Medicaid eligibility under Katie Beckett include but are not limited to: cerebral palsy with physical challenges, Down syndrome needing ongoing supervision, spina bifida, severe emotional disturbance, autism spectrum disorder, and cancer. Diagnosis alone does not make a child eligible. The determination depends on the degree of the individual child's functional limitations and his or her need for specialized care and services.

#### WHO IS ELIGIBLE FOR KATIE BECKETT?

The child must be under the age of 19 years and:

- The child must need an ongoing level of care given in hospitals, nursing homes, or in-patient care facilities. (For example: a child with an IV or G-tube living at home or receiving services in a facility like the Brattleboro Retreat or Northeastern Family Institute.)
- It must be medically appropriate to care for the child at home.
- The care the child receives at home must not cost more than the same care in a care facility.

Disability Determination Services in the Department for Children and Families determines if a child meets the disability and institutional level of care requirements. See Chapter 5 for help in making the case that your child qualifies for Katie Beckett.

#### WHAT ARE THE PREMIUMS FOR KATIE BECKETT?

There are no premiums for the Katie Beckett program.

#### **HOW DO I APPLY FOR KATIE BECKETT?**

To apply, call Health Access Member Services Unit at 1-800-250-8427 or your local DCF Economic Services Division District Office and ask for the Disabled Children's Home Care (Katie Beckett) waiver application forms to be sent to you.

These forms are complicated and take time and effort to complete. See Chapter 5 section on "Tips of Applying for Katie Beckett" for detailed information on how to fill out the application and put forward your case. If you need help filling out the application, contact Vermont Family Network or your local DCF office. You should make a copy of the application for your records in case the application is lost, because you will not want to complete it a second time.

Medicaid may pay medical bills incurred three months prior to a child becoming eligible for Katie Beckett. To obtain retroactive benefits, you should complete and file a DSW 202A Request for Retroactive Assistance.

#### DR. DYNASAUR OR KATIE BECKETT?

If you are above the income limit for Dr. Dynasaur, your child may still be eligible for Medicaid through the Katie Beckett program. If your child meets the eligibility guidelines for both Dr. Dynasaur and Katie Beckett programs, you should probably choose to apply for Dr. Dynasaur. The application is much quicker to fill out and easier to review and approve - and both programs give access to the same Medicaid benefits. However, if your income fluctuates so that sometimes your family is eligible for Dr. Dynasaur but sometimes might exceed the income amount (for example, if someone works seasonally or is planning to return to work or increase work hours) it might make sense to apply for Katie Beckett rather than Dr. Dynasaur so your child's coverage remains continuous.

#### **WAY #4: Home and Community-Based Waivers**

A waiver is a way the state can use Medicaid funding more flexibly to pay for services for a specific population instead of relying on institutionalized care. States can request that the federal government waive certain federal restrictions on how Medicaid dollars are spent to cover services that would otherwise not be covered by Medicaid. Vermont offers four waiver programs, including:

- Developmental Services Waiver (DS Waiver)
- Children's Mental Health Waiver (MH Waiver)
- Traumatic Brain Injury Waiver (TBI Waiver)
- Choices for Care Waiver (1115 Waiver)

A child or adult who is eligible for another of the six ways to access Medicaid may be able to get additional or specialized services through a home and community-based waiver, such as behavioral or job supports, home modifications, assistive devices, and more. Each waiver offers a different array of possible services.

In addition, a person who does not otherwise qualify for Medicaid might be found eligible for Medicaid through a waiver. For example, under the Developmental Services Waiver, waiver recipients are generally counted as a "one-person household," regardless of their present living arrangements. The family's income is "waived" or not counted. Only the income and resources of the person who has a developmental delay, cognitive impairment, or autism is counted.

One disadvantage of relying on Vermont's Medicaid waiver system is that benefits are not an entitlement. That is, access to waivers can be limited to the state funding available. Even if an individual meets the functional or diagnostic eligibility criteria for the waiver, he or she may not get all the needed benefits the waiver could potentially offer, or may not be approved for the waiver at all. Several of the waivers maintain "waiting lists" for services.

In the case of the Developmental Services Waiver, only individuals who have a critical need as defined in the "System of Care Plan" generally receive waiver funding. Children at risk of a possible outof-home placement or adults who have health and safety risks or need employment supports are generally considered priorities.

See the chart, at right, for more specific information on each waiver.

# **DEVELOPMENTAL SERVICES WAIVER** (DS WAIVER) **CHILDREN'S MENTAL HEALTH WAIVER** (MH WAIVER)

#### TRAUMATIC BRAIN INJURY WAIVER (TBI WAIVER)

#### **CHOICES FOR CARE WAIVER** (1115 WAIVER)

WHO IS ELIGIBLE?	WHAT SERVICES ARE AVAILABLE?	HOW DO I APPLY?
Individuals of all ages with a developmental disability (an intellectual disability as defined as a person with an IQ of 70 or below and significant deficits in adaptive behavior, or a pervasive developmental disorder) within funds available.	Services could include but are not limited to:	For more details, contact the Division of Developmental Services at the Vermont State Department of Developmental and Mental Health Services at (802) 241-2614.  You can also contact your local designated agency for more information. See Appendix C to find your local designated agency.
Children with a mental health condition or mental illness who are at risk for psychiatric hospitalization.	Services could include but are not limited to:	Call the Vermont Department of Mental Health at <b>(802) 828-3824</b> for more information or see Appendix C for the number of your local community mental health center.
Individuals with recent, moderate to severe traumatic brain injury, age 16 years or older at risk for being in and out of rehabilitation centers.	Services could include but are not limited to:	Contact the TBI Program Coordinator at the Department of Disability, Aging, and Independent Living at (802) 241-1228 or (802) 241-1456 for more information. You can download an application package, guidelines, and forms at: www.ddas.vermont.gov/ddas-programs/tbi/programs-tbi-default-page#applying
Vermont residents who are elderly, or aged 18 and over with a physical disability that meets specific clinical criteria. Individuals must also meet the income and resource eligibility criteria for Vermont Long-Term Care Medicaid.  (A second program is available for some individuals with moderate needs who need less assistance to stay at home. This program offers limited case management, adult day services, and/or homemaker service.)	Hands-on assistance with eating, bathing, toilet use, dressing, and transferring from bed to chair; assistance with tasks such as meal preparation, household chores, and medication management and increasing or maintaining independence.  Services could include but are not limited to:	Contact your local home health agency or area agency on aging. If you do not know your local home health agency, call the Department of Disability, Aging, and Independent Living at (802) 241-2880. To locate your Area Agency on Aging call 1-800-642-5119.  More information on Choices for Care can be found at www.ddas.vermont.gov/ddas-programs.

#### **WAY #5: Social Security Supplemental Security Income (SSI)**

#### WHAT IS SSI?

Supplemental Security Income (SSI) is a federal program for people with disabilities administered by the Social Security Administration. The child must be under age 18 and unmarried. If your child is found eligible for SSI then he or she is almost always eligible for Medicaid and would receive a monthly check from the Social Security Administration. The amount of the check will depend on the income and resources of the child and/or the child's household.

#### WHO IS ELIGIBLE FOR SSI?

Eligibility is based on a determination that the child is disabled and the family's (including the child's) financial situation.

#### **HOW IS FINANCIAL ELIGIBILITY DETERMINED FOR SSI?**

The Social Security Administration (SSA) determines a family's financial eligibility based on the following:

- Earned Income: Earned income is money from wages, tips, or self-employment.
- **Unearned Income**: Unearned income is money from child support, alimony, bank interest, unemployment compensation, Reach Up, disability trust income, etc.
- **Resources and Assets**: Resources are things that families own such as cash, bank accounts, stocks, bonds, houses, cars, and boats. Farm equipment, rental property, furniture and personal belongings may be resources. Parents may have \$3,000 in countable resources if two parents live at home, or \$2,000 if one parent is in the household. SSA considers any amount above that as belonging to the child. This is called *deeming*. If the amount deemed to the child, combined with any resources the child has, is under \$2,000, the child is eligible for SSI.

Some resources are *not* counted by the Social Security Administration, such as the house that you live in, and one car. Many factors are considered when determining financial eligibility. All families are encouraged to apply even if they feel they are slightly over the income/resource guidelines. SSA will determine whether you meet the income/resource guidelines.

There is another way for your child to be found eligible for SSI without counting parent income and/or resources. This is called a waiver of parental deeming. The child must:

- be under age 18 years old and disabled, and
- have previously received SSI, at the personal needs allowance level, while in a medical institution, (e.g. a hospital, intermediate care facility, Northeast Family Institute, etc.) for one calendar month or more, and
- be eligible for Medicaid from the state of Vermont under a home care plan, and
- be ineligible for SSI benefits because the parents' income and resources are over the limit set by the Social Security Administration.

The child who fits into these eligibility rules would be eligible to receive SSI benefits based solely on the eligible child's income and resources. Payments to the child would be based on the personal needs allowance. This payment is currently \$30.00 per month.

Very helpful information on SSI eligibility and benefits, including tables that show income levels for eligibility, can be found at www.ssa.gov/ssi/text-child-ussi.htm.

#### HOW IS DISABILITY DETERMINED FOR SSI?

Disability Determination Services (DDS) determines if your child's disability meets eligibility requirements based on information provided by medical providers, therapists, counselors, schools, and parents. Your child is considered to be disabled if he or she has a physical or mental condition which results in severe functional limitations, and the condition is expected to last at least 12 months or result in death.

Your family will be asked to list professionals who can provide information about the child's disability. This list should include anyone who can help document facts about the disability, including letters from physicians, therapists, teachers, day care providers, as well as family, friends, relatives, and/or others. Letters that describe the child's limitations are most helpful.

DDS can be reached at **1-800-734-2463**.

See Chapter 5 for more information about how to make the case for disability eligibility for SSI.

#### **HOW DO I APPLY FOR SSI FOR MY CHILD?**

Comprehensive information about applying for SSI for a child can be found at www.ssa.gov/applyfordisability/child.htm.

There are many ways to apply:

• Call the national Social Security Administration's (SSA) toll free line: **1-800-772-1213** (TTY 1-800-325-0778)

• To begin the application process, you can call or visit your local SSA office:

Burlington: 1-877-840-5776 Rutland: 1-866-690-1944 Montpelier: 1-877-505-4542

Some work can be done online or over the phone. A face to face interview is not required. The application can be completed by phone and mailed to the family for their signatures. The SSA will send your claim to Vermont's Disability Determination Services (DDS) for a medical decision.

#### **SOCIAL SECURITY APPEALS PROCESS**

The Social Security Administration denies applications for children's SSI benefits where the medical evidence in the claim does not meet the requirements for eligibility. It is not unusual for the initial application to be turned down.

These denials can be appealed and benefits are often approved after an appeal is decided. Benefits are retroactive to the date of the original application.

See Chapter 5 for more information on how to appeal a determination on SSI for your child.

Contact Vermont Family Network if you need assistance in applying for SSI or making an appeal.

#### **WAY #6: Categorical Need** (Other Special Circumstances)

There are a few special circumstances when an individual or family could qualify for Medicaid other than through the regular programs. The Ribicoff Option and the Medically Needy Spend Down program might help families with children with special health care needs who may not have access through the programs discussed thus far.

#### **RIBICOFF**

Vermont is one of 16 states that offer the Ribicoff eligibility option - named after the Connecticut Senator who championed it - that allows states to offer Medicaid to young people up to age 21. Some children who are in foster care, or who have been adopted, or who participate in one of the Green Mountain Care programs may be eligible for Medicaid (and EPSDT) through their 21st birthday.

#### MEDICALLY NEEDY SPEND DOWN

Medically Needy Spend Down is a program designed to assist people who have large out-of-pocket medical bills by subtracting those bills from their monthly net income. The lower income level is then used to determine financial eligibility for Medicaid.

If you temporarily have unusually large medical expenses, you may qualify for a medically needy spend down if you are:

- a child under 21 years of age or
- a pregnant woman or
- · disabled or blind or
- age 65 or older or
- the parent of a dependent child (under certain conditions)

An eligibility specialist can review your monthly income (if any), medical and other household expenses, household size, and resources. He or she will then determine if you might qualify for Medicaid. This process is very individualized.

We recommend that anyone who has unusually high medical expenses contact Health Access Member Services at 1-800-250-8427 for an application.

#### **Summary: Which Way is Best?**

A child could potentially qualify to access Medicaid in several ways. Which of the six ways is best for your child will depend on many factors, including family income and resources, parent employment status, whether there are other adults or children in the family, your child's special needs, and the premiums charged (or not) for each program and your ability to pay them.

Vermont Family Network is available to help determine which program may be best for your child and to assist you with the application process.

For questions regarding any Vermont Medicaid program, please call Vermont Health Access Member Services at 1-800-250-8427 or contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org.



## **Benefits of Medicaid** and EPSDT

Children from birth to 21 years who are eligible for Medicaid are entitled to services known as Early Periodic Screening, Diagnosis and Treatment (EPSDT).

EPSDT was enacted by Congress in 1967, "to reduce infant mortality and improve access to child health services." It is the most comprehensive child health program in either the public or private sector.

Screening must include medical, dental, vision and hearing. EPSDT includes immunizations, laboratory tests, and health education. Treatment must include any necessary diagnostic services, health care, or measures to "correct or ameliorate" a health condition. States are mandated to inform all people with Medicaid about EPSDT services and how to access them. There are many services that children are entitled to under EPSDT as long as a licensed practitioner feels they are medically necessary. Services are provided in the amount prescribed, that is, in the frequency and amount a provider feels the services are needed.

Services must be delivered in a setting that is appropriate to the specific health needs of the individual (for example, an individual's home, school, child care center, workplace, or community-based agency).

Some things like eyeglasses, supplies, and equipment might be limited to "Medicaid approved" models or types. There may be other limitations on the duration and intensity of services. This chapter will provide more detail about the benefits and limitations of Medicaid coverage for children.

#### **EARLY PERIODIC SCREENING, DIAGNOSIS, AND** TREATMENT (EPSDT) SERVICES

ambulance

audiology

augmentative communication devices

certified nurse midwife

Children with Special Health Needs clinics (if enrolled)

chiropractic services

#### dental care:

- preventative
- restorative
- periodontic
- emergency care
- · some orthodontics

diabetic supplies

doctor visits, primary care, comprehensive health exam

doctor visits, specialists and second opinion

durable medical equipment:

- assistive technology
- · wheelchairs
- monitors

emergency room

enteral/parenteral nutritional formula

eye exams

eyeglasses

family planning (birth control)

formula for PKU

gynecologist (women's health care)

hearing aids

home health nursing

home health aid

hospice care

immunizations

inpatient hospital

inpatient rehabilitation

lab tests and screenings:

- hearing and vision
- dental
- lead testing
- · x-ray, MRI and CT scans
- EKG and EEG
- · other testing for conditions or delays

maternity care

medical supplies

· diapers for children over age three)

mental health services

nutrition and dietician services

occupational therapy

organ transplants

orthotics

outpatient hospital care

over-the-counter drugs (with prescription)

pediatric specialists

- neurologists
- cardiologists
- urologists

personal care services

physical therapy

podiatry

prescription drugs

prosthetics

respiratory therapy

service coordination

skilled nursing facility

speech therapy

substance abuse treatment

surgery

transportation (to and from medical appointments)

well child visits

#### **Medicaid Benefits and Programs for** Children with Significant Disabilities or Chronic Conditions

Many services and therapies required by EPSDT are not provided by commercial health insurance policies (for example, personal care or mental health services). Medicaid EPSDT can be invaluable for children with significant disabilities or chronic conditions because it covers these services.

In addition, Vermont provides some program benefits for children with special needs who meet certain criteria, including Mental Health and Developmental Services Waivers, High Technology Home Care, and palliative care. These and some other special benefits are described here.

#### **MENTAL HEALTH SERVICES**

When your child is eligible for Medicaid, some public mental health services are available and can be accessed through the designated agency (DA) in your area.

A child on Medicaid may qualify for case management, in-home therapeutic supports, or other services delivered through the DA in the community setting. Some therapists in private practice also accept Medicaid.

If there is an immediate crisis, you may want to access other services first. But children ages 0-22 years old with serious emotional disturbance or who continually struggle with school or community life can also access an interagency Act 264 Coordinated Services Plan (CSP) through the child's school or mental health provider. A team of professionals representing education, mental health, the family, and DCF will come together to explore additional supports for child and family. Please note that while your child has a right to a plan, there is no guarantee of funding for therapeutic activities. However, most teams attempt to create a plan that will be effective and realistic for the family. In addition, families should be aware that even if the school, interagency team, family, or child recommends a residential placement, the only way for a child to get Medicaid coverage for a residential treatment program is to go through the Act 264 process. Vermont Family Network can provide information and guidance about the CSP process.

Cases that cannot be resolved at the ACT 264 partnership level may be referred to the **Local Interagency Team (LIT)** and, at their discretion, to the **State Interagency Team (SIT)**. Parents may request a parent representative to attend meetings with them by checking the box at the bottom of page two on the CSP consent form. If you would like to contact the LIT parent representative in your area, please call the Vermont Federation of Families for Children's Mental Health (VFF) at 1-800-639-6071 or visit www.vffcmh.org.

#### **PERSONAL CARE SERVICES**

Children's Personal Care Services (assistance with daily activities) are available through Medicaid EPSDT to a child under 21 with a significant disability or health condition, when medically necessary. A child with a physical, behavioral or cognitive problem might be eligible to receive assistance from a personal care attendant (PCA) if he or she has difficulty with carrying out some (or all) of the following *activities of daily living (ADLs)*: bathing, dressing, feeding, toileting, grooming, positioning, transferring, or walking.

Examples of children who might receive personal care services include:

- a 7 year old child with cerebral palsy who cannot bathe or feed him or herself independently.
- an 11 year old with autism spectrum disorder who needs constant supervision to carry out "activities of daily living" (ADL) such as dressing and grooming because of a challenging behavior.
- a child who wanders or doesn't understand danger or engages in risky or unsafe behaviors.

If a child is approved for Children's Personal Care Services (CPCS), the personal care attendant will assist the child and family with personal care activities for a certain number of hours each week, as determined by CPCS. The attendant will also assist in carrying out the child's care plan (e.g. behavior or feeding plan).

Personal care services can be provided through a local agency that provides personal care services appropriate for the child's diagnosis or condition like the Visiting Nurse Association (VNA), other local home health agencies, specialty services agencies, or certified providers. Some local developmental service and community mental health agencies provide personal care services, especially for children with emotional, behavioral, or cognitive limitations.

Personal care services can also be provided by someone the family chooses to hire and train under the self-management option. Generally, PCAs can be family members over age 18, but not the parent, partner, or foster parent of the child. (Sometimes an individual under age 18 can be approved, but you must ask for approval first.) If a family employs the PCA, payments are made through Aris Solutions (ARIS), 1-800-798-1658.

To apply, a Children's Personal Care Services (CPCS) assessment must be completed by a qualified assessor to determine the medical necessity and service level (hours allotted) to be provided by the PCA. CPCS assessments can be performed by home health, developmental service, and mental health agencies as well as physicians, social workers, early intervention, CSHN, and Vermont Family Network staff.

For questions and information about the Children's Personal Care Services Program contact CPCS at 1-888-268-4860. Assessing agencies and contact numbers by county are available by calling this number and in the CPCS program brochure at www.ddas.vermont.gov/ddas-programs/ programs-cpcs-default-page.

#### HIGH TECHNOLOGY HOME CARE

The High Technology Home Care Program is for children and adults who are dependent on technology to survive. The goals of the program are to support a transition home from the hospital or other institutional setting and to prevent institutional placement. To apply or for more information, call the Division of Disability and Aging Services (DDAS) at (802) 241-4639 or visit www.dail.vermont.gov for individuals age 21 and older. For children up to age 21, contact Children with Special Needs at (802) 865-1327.

#### HOME AND COMMUNITY-BASED WAIVERS

Waivers serve individuals with disabilities in the community. Waivers may be able to offer more benefits than the standard package of EPSDT, including habilitation services which help children acquire the skills necessary to perform activities of daily living.

As discussed in more detail in Chapter 3, the waivers that may be available to some children or young adults in Vermont include:

- Developmental Services
- · Children's Mental Health
- Traumatic Brain Injury
- Choices for Care

#### **HOSPICE AND PALLIATIVE CARE**

Effective July 1, 2011, Vermont Medicaid provides expanded hospice and palliative care for children with life-limiting illness and their families. Benefits include care coordination, respite for the child's caregivers, expressive therapies, and training and bereavement counseling for family members. These hospice and palliative care benefits will be provided along with curative treatment and health care for the child. For more information about palliative care, call Children with Special Needs at 1-800-660-4427.

#### CARE COORDINATION: THE BRIDGE PROGRAM

The Bridge Program helps families of Medicaid eligible children with developmental disabilities under age 22 to access and coordinate medical, educational, social, or other services. The

#### Bridge Program can:

- help families determine what supports or services are needed;
- help families access needed services to address their child's needs:
- help families coordinate multiple services and develop a coordinated plan to address needs.

Contact your local Developmental Disability Designated Agency for information about applying for the Bridge Program. You can find contact information for the agency in your region by calling (802) 241-2614.

# Challenges and Limitations on Benefits in Medicaid

The Department of Vermont Health Access (DVHA) may require that you or your provider fill out additional paperwork to access certain benefits or receive certain benefits. In addition, despite the generous package of Medicaid EPSDT benefits for children, there are often limitations on the amount or type of service or item provided. Coordination of Medicaid with other insurance or services and health care provided to your child outside of Vermont can also be challenging and frustrating for families.

It is helpful if families understand some basic Medicaid limitations and process requirements. This section will discuss some of them.



#### **MEDICAID COVERED SERVICES**

Medicaid will only pay for covered services that are part of the state's Medicaid Plan. Fortunately, because of the legal requirements of EPSDT, most health care services are covered for children under Medicaid. After a child's 21st birthday, Medicaid benefits (for example dental and vision benefits) are significantly reduced.

#### **MEDICAL NECESSITY**

Any child eligible for Medicaid is entitled to these EPSDT services if a licensed practitioner states the service is medically necessary. Services may be provided only in the amount prescribed which means only for as often or for as long as the provider recommends.

According to the United States Department of Health and Human Services, a covered service or item is medically necessary if it will do, or is reasonably expected to do, one or more of the following:

- arrive at a correct medical diagnosis;
- prevent the onset of an illness, condition, injury, or a disability;
- reduce, correct, or ameliorate the physical, mental, developmental, or behavioral effects of an illness, condition, injury, or disability;
- assist the individual to achieve or maintain sufficient functional capacity to perform age-appropriate or developmentally appropriate daily activities.

The determination of medical necessity must be made on an individual basis and must consider the functional capacity of the person. The decision must be based on the capacities that would be appropriate for persons of the same age or developmental level and on health care practice guidelines, research, and standards issued by professionally recognized organizations or government agencies.

Sometimes families feel that their child is being denied services that he or she needs, or is being limited to less duration and intensity of therapy than medically needed. Families should be aware that if a doctor is recommending a service on the EPSDT list and all needed documentation has been filed and the Vermont Department of Vermont Health Access (DVHA) is still not approving the service or medical item, it may be worth fighting.

See Chapter 5 on "Advocating for Eligibility and Benefits for Your Child" and Chapter 6 on "Grievance and Appeals" for more detailed information on how to advocate for medical necessity for your child, or call Vermont Family Network.

#### **PRIOR AUTHORIZATION**

Sometimes a therapy, service, procedure, or purchase of a piece of medical equipment may require prior authorization from various state departments that administer Medicaid, depending on which service.

Your provider will know these prior authorization rules, and they will ask for the prior approval for you. These guidelines are very complex and detailed. They are posted on the "provider" section of the Department of Vermont Health Access website at http://dvha.vermont.gov/for-providers/ clinical-coverage-guidelines.

#### **Coordination of Benefits**

#### COORDINATION WITH PRIVATE INSURANCE

If you have a primary insurance other than Medicaid, claims will be processed first by the commercial insurance. Any appeals to insurance company decisions will be with that primary insurance company. As a secondary insurer, Medicaid accepts and follows the lead of the primary company. Medicaid will not require preauthorization for items previously pre-authorized by primary private insurance.

If Medicaid is the primary insurance, then Medicaid policies prevail. Medicaid may be more stringent or more lenient than some private insurance, depending on the type of service or medical supply or equipment claimed. When Medicaid is primary, prior authorization for procedures, durable medical equipment (DME), out of state medical care, and other medical appointments may be necessary.

#### COORDINATION WITH SCHOOL SERVICES

Coordination of Medicaid and school services for children with developmental disabilities can be very complex. Except under waivers, Medicaid can only pay for rehabilitation services that restore functional losses. For children with developmental disabilities, *habilitation services* to *develop* (as opposed to *restore*) functional abilities are very important. Schools play an important role in providing both those skills to children with developmental disabilities, but can only bill Medicaid for rehabilitation services, and not habilitation services, unless a child is covered under a waiver. Services must be specified in the child's IEP, and schools may differ in the degree to which they provide Medicaid services that are important to the child's development.

#### **COORDINATION WITH OTHER PROGRAMS**

Children with special needs may also receive services and benefits from programs like early intervention programs from birth to age three and/or from the Children with Special Health Needs Program (CSHN) as described in Chapter 3. These programs will coordinate benefits and bill insurance, including Medicaid, first.

The CSHN program is the *payor of last resort*, that is, CSHN will pay only when all other private insurance companies, and Medicaid, have paid out as much as allowable for CSHN covered services.

#### **COORDINATION OF AND ACCESS TO OUT OF STATE CARE**

Sometimes because of a diagnosis, you may need to take your child out of state to get the appropriate medical care. Often doctors will refer patients for out of state care if they know that they cannot provide the service your child needs. Sometimes you may need to do some research to get your child the medical care he or she needs. Each situation is different.

Whether your goal is to research the best doctor for your child's unique diagnosis or it is an emergency situation that needs immediate attention, here are some things to consider:

- Whether or not your primary insurance covers out-ofnetwork coverage (note: out-of-network is not always just out of state). For example, a hospital like Dartmouth Hitchcock may be considered in-network for your insurance even though it is in New Hampshire.
- If you have Medicaid, out of state services may not be covered. This depends on whether or not the service can be provided in-network and whether or not the provider will accept Vermont Medicaid.

Travel expenses may be partially covered by your primary insurance or by Medicaid. Also, there are non-profits that sometimes will help with expenses for children with a specific diagnosis.

#### Summary

Coordinating health care programs and insurance benefits can be very confusing, time consuming, and frustrating for parents and providers. Vermont Family Network can help you understand and navigate them.

Call Vermont Health Access Member Services at 1-800-250-8427 or contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org.



# Advocating for Eligibility and Benefits for Your Child

Advocating for your child is one of parents' most critical roles. It can be a daunting role but with knowledge, support and planning you can do it successfully. Always remember that you know your child best.

### **General Suggestions**

It is very important to get an accurate diagnosis for your child's health problem or disability to determine needed services and to access insurance benefits and/or appropriate public programs and resources. Concerns about giving your child a "label" must be balanced with the practical need to access the services your child requires. It may be helpful to discuss with your child's doctor the best words to use to describe your child's condition.

If the diagnosis is given through an evaluation process, it is important that you be fully involved and ask many questions. Be sure you understand the results of the evaluation, your child's diagnosis, and the full range of medical, educational or mental health needs and options, including accommodations. Become familiar with the programs that may be available to support or assist you and your child. Vermont Family Network can help you identify and connect to services and programs.

#### **DOCUMENTATION AND ORGANIZATION**

It is very important to keep records about your child's disability. This includes evaluations, IFSPs, IEPs, and medical (including specialist and therapist) or mental health reports. This information is the backbone of eligibility and benefits for your child. Keep this information in some sort of organized manner. Vermont

Family Network has binders with designated tabs and helpful print outs that help guide you in organization. The binders keep things orderly, easy to find, and portable.

It is also essential to keep acceptance and denial paperwork that you may receive from SSI or your insurance, whether it be an HMO or Medicaid. You should go over this paperwork carefully when you receive it so that you understand it. The paperwork may also have information on it with telephone numbers that explain next steps you can or should take. Be sure to send any extra needed documentation requested as soon as is possible. Always make copies of any application, information, or letter that you send. It is wise to keep documentation of any telephone contacts you have made with date, time, and discussion content.

When trying to prove eligibility or needed benefits, it is essential that you document your view of a "day in the life" of your child. This is often a difficult task as when we view our child, we see all his or her strengths. In this document you will want to go through a 24 hour day of what you do for your child that is above and beyond what you had to do for your other children when they were the same age. You will need to think about and notice all the extra help, mentoring, cueing, reminders and accommodations that you do that have become routine, and write about his or her challenges. Be sure to note medical appointments, specialty clinics, therapy visits, counseling, social skills training, and all the speech and language, occupational and physical therapies that you incorporate into your child's daily routines. It is also necessary to have up to date information from doctors and therapists documenting your child's disability.

#### **FOLLOW THROUGH**

It is imperative to follow up with everything that is requested. Denials are often the result of the determining agency not having all the information or evaluations needed. It is acceptable to call a department or agency to ask about whether your application is complete and where your application or denial is in the process, and it may help keep things on a good timeline.

#### **SUPPORT**

Remember that you know your child best and you can respectfully disagree when you feel someone has misinterpreted something or has inaccurate information. When working through a denial of disability or service, it is important to remain calm, keep your facts straight, and appeal as needed.

Vermont Family Network can help you understand applications, eligibility, denials, and special education or other educational services and accommodations. We are here to help you navigate the unfamiliar systems you find yourself in when advocating for

your child. We also sponsor workshops on advocacy, partnering with professionals, and family leadership.

It is very helpful to talk with other parents who have gone through the same process. Vermont Family Network can connect you with parents who are trained to support and share the knowledge they have gained through their own experiences. Another choice is to join a support group. Read, explore reputable websites, and connect to area resources.

When needed, the Disability Law Project of Vermont Legal Aid and the Health Care Ombudsman are excellent legal resources. (See Chapter 6 on Grievance and Appeals.)

#### **BUILD PARTNERSHIPS**

Working with your child's pediatrician or doctor on a Medical Home for your child is extremely important. A partnership between family and doctor with good communication is crucial. It is equally important to have a working relationship with the all the providers on your child's team, including school staff. Educate, ask questions, keep contact lists, keep records, and "get it in writing."



#### **Advocating for Katie Beckett**

When applying for Katie Beckett, answer every question on the Green Mountain Care Program application, but answer the questions as if your child were the one filling out the form. Example: Your child's name goes in the applicant space and you put your child's income and resources down, not your family's.

On the Disability Social Report (Child) answer all the questions unless you get to parts that are not appropriate to answer for your child. (For example, education or work history questions that do not apply to your child because of age.)

List all the names of those who provide services or supports for your child (therapists, medical providers, counselors, special educators, etc.). If there is not room in the application for all the service providers, you can attach your list to the Disability Social Report (Child). Section 11 is to be filled out by an Economic Services Division worker.

The following are optional to include with your application, but can help speed up the process and help the agency determine that your child is eligible:

- Copies of your child's medical records that document your child's disability.
- Document your parent or parents' view of a "day in the life" of your child as described earlier in this chapter.
- Obtain and include letters from service providers about your child's disability.

When Disability Determination Services does not receive all the information about your child, they may deny your child's application even if your child should be eligible. Vermont Family Network can assist you with interpreting the denial and with the appeal process. The Disability Law Project may be able to advise and provide representation about your appeal. (See Chapter 6.)

The application takes time and effort to fill out. You should make a copy of the application and paperwork sent with it for your records in case the application is lost.

If you receive a denial, an appeal for Katie Beckett eligibility goes to the Human Services Board at 14-16 Baldwin St., Second Floor, Montpelier, Vermont 05633-4302.

An appeal may also be initiated by making a written or oral statement to any department or office in the Agency of Human Services that you wish to have your case reviewed by a higher authority. The department or office is then required to assist you in submitting a request for fair hearing and refer you to legal representation. The department or office must send any request for hearing to the Human Services Board.

# Advocating for Supplemental Security Income (SSI)

The Social Security Agency (SSA) will ask for documents to support your child's SSI application. SSA needs to see the originals, not photocopies. Please have your documents on disability, income, and resources ready for the interview. The claims representative will copy the documents and return them.

Please be on time for your interview as they will have back-to-back interviews scheduled. (Being late will probably mean you will have to schedule another interview time.) At this time, SSI may have you sign the paperwork, or if it is a phone interview, will send you the paperwork to look over, sign, and mail back.

Do not wait to file an application, even if you don't have all of the medical information for your child. Social Security pays benefits back to the application date, so file as early as possible and then get whatever other documents are necessary to complete the process. The time from when you make the initial call to SSA and receiving a written notice from them, stating approval or denial, can be three to five months.

Your medical sources will not be asked whether your child is disabled. That determination is made by a state agency team, which includes a disability examiner and a medical consultant.

Usually, the team gets enough evidence from your medical sources to make a decision. However, if more evidence is needed, a special exam will be arranged and paid for by Disability Determination Services (DDS). It is your responsibility to bring your child to the appointment. If you are eligible for mileage reimbursement, you will receive a travel voucher with the notice of the appointment. If you have problems arranging transportation, whether or not you received a travel voucher, call DDS immediately. With enough lead time they may be able to help you arrange transportation.

If your claim is approved, you will receive a notice showing the amount of your benefit and when payments will begin. If the claim is denied, the notice will provide an explanation of the denial. Read the denial carefully as it will give you information on why your child was denied.

#### TO APPEAL AN SSI DETERMINATION

If you disagree with the determination, you must request that your case be reconsidered within 60 days from the day you receive the letter informing you of the decision. You will be asked to fill out some more forms about any changes in your child's condition and any new medical treatment.

Some of the reasons to request reconsideration are: a) the condition is more severe than determined, b) the condition has

lasted longer than expected, c) the condition has worsened since the decision, d) the condition became disabling earlier than determined, or e) another condition developed that complicates the first condition.

If your child's application was recently denied for medical reasons, you may request an appeal on the Social Security Administration's Internet Appeal website https://secure.ssa. gov/apps6z/iappeals/ap001.jsp. There are two parts to the internet appeal process:

- an Appeal Request Internet Form, and
- an Appeal Disability Report that provides more information about your child's condition.

If you do not want to request an appeal via the internet, or if your application was recently denied for non-medical reasons, you may either:

- Contact your local Social Security Office by phone or in person and tell the representative that you want to appeal the decision made on your case, or
- Call SSA toll-free at 1-800-772-1213. Explain that you don't want to use the online appeal process but do want to appeal the decision made in your case. Representatives are available Monday through Friday from 7 am to 7 pm. Call the toll-free TTY number if you are deaf or hard of hearing: 1-800-325-0778.



The reconsideration case is returned to Disability Determination Services where it is handled by a different examiner and medical consultant. Evidence from the original decision and any new evidence are considered. Once again, medical evidence is obtained, and an independent decision is made.

Always keep records whenever you call the SSA about your child. Jot down the date, time, and who you talked with, along with a description of what you discussed. There are multiple levels of appeal for Social Security decisions so you may want to contact the Disability Law Project of Vermont Legal Aid or Vermont Family Network for advice.

#### **Advocating for School Services**

When your child enters school, his or her educational needs and a lot of his services and therapies will be through his Individualized Education Program (IEP).

As the parent of a student with a disability, you are a valuable part of his IEP team and will be asked to attend lots of different types of meetings. Sometimes you will need to request a meeting. A conference with the IEP team or school principal can be stressful for any parent. If the student is having trouble in school or the parent disagrees with the services or placement that the school district is proposing, the level of stress increases.

These tips may help you be better prepared and effective in advocating for school services for your child.

#### **BEFORE THE MEETING:**

- Know the reason for the meeting. The notice may tell you
  what the school or district wants to discuss with you, but
  the meeting is also an opportunity for you to discuss your
  concerns with them. If you have called the meeting, make
  sure your purpose is clear. It is helpful to make a list of your
  issues to bring so you won't forget to talk about what is
  important to you. You can also contact the facilitator of the
  meeting ahead of time to ask to have your items added to
  the agenda.
- Note who will be present at the meeting. Be sure all key people are included. For example, if medical issues will be discussed, ask that the school nurse be present.
- Bring documentation to back up your requests and/or concerns. Be prepared! Consult with your child's doctor, therapists, or mental health counselor. If needed, invite them to participate in the meeting or ask them to write a note about the student's diagnosis, symptoms, and services or needs at school.
- Review your guide to special education services. It is

- important that you know what rules or procedures the school will be following and what your rights are if you disagree with the meeting's outcome. If you are unsure about the meeting and how to talk about your concerns or child's needs, call Vermont Family Network and talk with one of the Family Support Consultants that can help you understand your rights and the meeting. She can help you sort out your thoughts and brainstorm ideas on the best way to present your thoughts during the meeting.
- It is a good idea for both parents to attend the IEP or Section 504 meetings. If that is not possible, then you should feel free to bring along anyone who is knowledgeable about the student or special education process and (most importantly) whom you trust. This person can help you take notes, etc.

#### **DURING THE MEETING:**

- Make sure that you know who is responsible for taking meeting notes, but take your own notes as well.
- Remain calm and be courteous. This can be very hard to do when you disagree with what is being said.
- Stay focused. This can be very difficult during a tensionfilled meeting. Use your list of issues to help keep yourself focused and keep the meeting on track.
- Make sure that there is a discussion of the student's strengths and abilities as well as any challenges.
- Always read everything that you are asked to sign. This
  includes attendance or sign-in sheets. If you don't understand what it is you are being asked to sign, don't sign it.
  Ask the team to help you understand the document.
- If you don't agree with the information stated on the paper, don't sign it. This is especially important when attending an IEP or Section 504 meeting.
- Ask for copies of the meeting notes and anything else that you were asked to sign at the meeting. Keep these. They may come in handy in the future if you and the school or district cannot agree about what was said at the meeting.
- Know what happens next. At the end of the meeting, make sure you know what is supposed to happen next and who is responsible. If you are not sure who is supposed to do what, ask before the meeting comes to an end and everyone leaves.

#### **AFTER THE MEETING:**

- If you noticed any errors in the meeting notes, ask to have the notes amended. Request to have a copy of the amended version in your child's file.
- Follow up with school staff to make sure they receive everything you send them.
- If you do not agree with the decisions made at the meeting or if you have questions that are not answered, you can get help from Vermont Family Network.

# If You Feel Your Child's Needs are Not Being Met by Local, State, or School Services

If you feel that your child's needs are not being met by existing services or Vermont Agency of Human Services (AHS) providers or contractors, or that the complexities of your situation are not being understood, contact your AHS Field Director. A Field Director is available in each of the 12 AHS districts of the state to unify human services and to build a system focused on excellent customer service, the holistic needs of individuals and families, strength-based relationships, and improving results for Vermonters.

Please contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org if you want more information or support about these topics.

#### **VERMONT AGENCY OF HUMAN SERVICES FIELD DIRECTORS**

Barre	(802) 479-7594
Bennington	(802) 447-2745
Brattleboro	(802) 257-2573
Burlington	. (802) 651-1684 or (802) 652-6852
Hartford	(802) 295-4115
Middlebury	(802) 388-5381
Morrisville	(802) 888-1330
Newport	(802) 334-3915
Rutland	(802) 786-5952
St. Albans	(802) 527-5438
St. Johnsbury	(802) 751-0168
Springfield	(802) 885-8862



# Grievance and Appeals

#### What is a Grievance or Appeal?

Problems arise with health care insurance coverage. Chapter 5 provided helpful information on how to advocate for your child but sometimes, despite your best efforts, you may need to formally complain about things like denial of eligibility or benefits, billing problems, or delays in services. The *grievance and appeals* process is a way to resolve issues with a health insurance provider.

#### **BACKGROUND**

A grievance is an internal process that is based on dissatisfaction with how the staff is doing their job. So you might file a grievance complaining that your child's developmental services home provider is treating you rudely, or that an insurance or state

agency person isn't returning your phone calls. Grievances are generally worked out informally.

An appeal is a formal legal challenge to a denial of eligibility or service. The appeal may be internal to the insurance company or the state department, or external (for example, to the Human Services Board).

There is a grievance and appeals process to help you solve problems for every type of health insurance:

- commercial health care insurance including managed care
- employer sponsored self-insurance plans
- Medicaid
- Vermont Health Access Plan (VHAP)
- Medicare

Each entity has its own procedure, but the process is very similar.

If you have any of these problems, Vermont Family Network is available to help you understand the issues and discuss your options. Call 1-800-800-4005.

Don't forget to keep records whenever you talk to anyone about your complaint. Jot down the date, time, and the name of the person you talked to, along with a description of what you talked about.

#### How Do I Start a Grievance or **Appeals Process?**

- The first step in the appeals process is to read your notice of denial carefully. This should outline the process and timelines for appeal.
- · Call your health care insurance provider to ask how their appeal process works if you have further questions.
- Request an internal appeal through your health care insurance provider or request a Medicaid Reconsideration, Appeal, or Fair Hearing.
- If your appeal involves questions of eligibility, be sure to keep aware of timelines and procedures for appeal so you do not lose coverage in the interim.



#### **Internal Medicaid Grievance and Appeals Options**

If you don't agree with a decision from the Department of Vermont Health Access (DVHA) to deny, limit, reduce or stop a service, you may ask them to review that decision.

You may also ask for a review if they don't act when they said they would. Contact Member Services to ask for a reconsideration, appeal, or fair hearing by calling 1-800-250-8427 (TTY 1-888-834-7898) or writing to:

**Health Access Member Services** Office of Vermont Health Access 101 Cherry Street, Suite 320 Burlington, VT 05401

If another department made the decision, you can contact that department. There will be contact information in the decision letter.

#### RECONSIDERATION

Reconsideration may help you solve your problem quickly, with a less formal process than an appeal or fair hearing. You or your provider may ask the department that made the decision to reconsider it. You or your provider may give the state agency more information or clarify what you have already provided. The person who made the decision will review your case and look at any new information, which may result in a new decision. Reconsideration is optional. You can choose to go directly to an appeal or fair hearing.

#### **APPEAL**

An appeal is heard by a qualified person who was not involved in the original decision. You and your provider will be invited to a meeting with this person to explain your viewpoint. If you have someone who represents you, they may come to this meeting as well. This meeting can also take place on the phone. At the meeting, you will be able to present your case for why you think the decision is wrong. You have 90 days from the date the decision was mailed to ask for an appeal. If you think your child's health will be seriously harmed, you may ask for an expedited appeal.

#### **FAIR HEARING**

Fair Hearing is a process that involves a hearing before a neutral hearing officer who then makes a written recommendation to the Human Services Board. Fair Hearings and Appeals may be requested simultaneously.

## **Help with Grievance and Appeals Processes**

If you are unsure of next steps or the review by your insurance company or Medicaid doesn't solve your problem, you may want to contact the organizations listed here to guide you through the next steps in the grievance and appeals process. These organizations can help you understand the issue, refer you to appropriate agencies that can help you, and/or be an advocate for you in addressing your concerns.

Organizations that can help in case of grievance or appeal include:

- Office of Health Care Ombudsman 1-800-917-7787
- Department of Banking, Insurance, Securities and Health Care Administration (BISHCA) 1-800-631-7788
- Vermont Legal Aid Disability Law Project 1-800-747-5022
- Vermont Family Network: 1-800-800-4005

#### OFFICE OF HEALTH CARE OMBUDSMAN

The Office of Health Care Ombudsman was created in 1999 to assist Vermonters with health insurance concerns and problems. It is a special project of Vermont Legal Aid, Inc., located in the Burlington Legal Aid office. The office is staffed by the Health Care Ombudsman and health care counselors. Their services are available to all Vermonters regardless of income or resources and they can assist with any type of health insurance coverage.

The counselors staff a state-wide toll free number. They answer questions, make available consumer education materials, refer to appropriate agencies, and advocate for and assist health care consumers in resolving health care issues and problems. Examples of issues they can help with are access to health care, billing problems, denials of care, delays in receiving care, and continuation of health insurance when changing employers or following loss of employment.

The Office also serves as a public voice for health care consumers in Vermont by commenting on federal and state health care regulations, providing the legislature and the public with information about health care issues in Vermont, monitoring and analyzing developments in health care, and recommending needed changes to the health care system.

The Office of Health Care Ombudsman can be reached at **1-800-917-7787** or (toll free TTY: 1-888-884-1955.)

### **DEPARTMENT OF BANKING, INSURANCE, SECURITIES AND HEALTH CARE ADMINISTRATION (BISHCA)**

The Health Care Division of the Department of Banking, Insurance, Securities and Health Care Administration (BISHCA) Consumer Services Specialists can assist consumers with

questions and concerns about private health insurance plans licensed by the state and can also refer consumers to other agencies and programs as needed. Complaints are monitored closely so that appropriate action can be taken by the Division to address major and persistent problems.

BISHCA's consumer services specialists can be reached at 1-800-631-7788 (toll free in Vermont) or (802) 828-2900.

#### **VERMONT LEGAL AID: DISABILITY LAW PROJECT**

The Disability Law Project provides free legal assistance to people whose legal problems arise from their disability in matters such as abuse and neglect, special education, guardianship, Supplemental Security Income (SSI), Medicaid, accessibility, and discrimination. Among the priorities of the Disability Law Project are providing assistance to children and adults with disabilities who need assistive technology devices or services to receive an appropriate education, gain or maintain employment, or live independently or participate in the community.

#### TO CONTACT VERMONT LEGAL AID:

Local Office	Address	Phone	
Chittenden,	264 No. Winooski Avenue	(802) 863-5620	
Franklin, Grand Isle,	PO Box 1367	1-800-747-5022	
Addison	Burlington, VT 05402		
Washington, Orange,	7 Court Street	(802) 223-6377	
Lamoille, Caledonia,	PO Box 606	1-800-789-4195	
Essex, Orleans	Montpelier, VT 05601		
Rutland,	57 North Main Street	(802) 775-0021	
Bennington	Rutland, VT 05701	1-800-769-7459	
Windsor,	56 Main Street, Suite 301	(802) 885-5181	
Windham	Springfield, VT 05156	1-800-769-9164	

# **Summary**

You may need to use a grievance or appeals process to access benefits that your child needs and is entitled to have. Don't be afraid to ask any of these organizations for help.

Please contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org if you want more information or support about these topics.



# Transition to Adulthood for Children with Special Needs

As children transition to adulthood, major changes occur for youth and their parents. Some young people may assert themselves and become more independent. Many parents will have apprehension about whether their son or daughter is really ready to deal with some of the challenges.

The same thing happens with other youth, though the situation can be far more complex when special needs are involved. In some situations, the youth may have significant needs that will limit his or her independence or even participation in managing his or her own needs.

The kinds of programs that serve children begin to change too. Special education services and school activities end or phase out by the end of the child's 21st year, depending on the school district and the youth's transition plan. Adult waivers or services often

replace Medicaid Children's Mental Health and Developmental Services Waivers. Other health care or support programs may end at the 21st birthday, while new ones may be available.

This chapter will provide information for transition-age youth and their families to help plan for future health care coverage and services.

# **Health Insurance Coverage at Age 18**

Thanks to the federal Affordable Care Act, private insurers that offer coverage to children under their parents' policy must now allow children to remain on their parents' policy until they turn 26

(unless the adult child has another offer of job-based coverage, in some cases). For families whose children have been covered under private insurance plans, this may be helpful through the transition years.

For children previously covered by public insurance programs, options may change in the years between 18 and 21. While the Dr. Dynasaur program is available to children only up to age 18, and Katie Beckett eligibility ends at 19 years, Medicaid benefits may still be available for some youth until age 21. States are required to continue to offer EPSDT benefits to any Medicaideligible children until age 21.

State Medicaid waivers for adults and certain other types of Green Mountain Health Care insurance (such as VHAP or Catamount) become available to youth with or without disabilities or chronic conditions at age 18. Other public insurance options are currently under development in Vermont.

Although some of these programs would not provide EPSDT benefits, they may be adequate to meet your youth's needs. The Medicare federal health insurance program and the federal cash assistance programs of Social Security and Supplemental Security Income (SSI) may also become available to some young adults with disabilities and chronic conditions.

Determining which of these programs, or which combination of these programs, are available to your young adult and which insurance programs provide the best coverage for the least expense can be a complex decision. It will depend on health status, disability, and individual (and sometimes family) income and resources. The information in this chapter is intended to help provide background on each of these programs. If you have any questions about health insurance at age 18, contact Vermont Family Network for information.

#### **School Services**

Under the Individuals with Disabilities in Education Act (IDEA), transition planning from school to adult life begins, at the latest, during high school. It is required, by law, to start during the year in which the student will reach 16 years of age.

Transition planning can begin at a younger age if the team feels that it is appropriate. The transition plan becomes a formal part of the student's Individualized Education Program (IEP). The parents and student should be part of the IEP team.

The student should be encouraged to participate as fully as possible in the creation of his or her transition plan. Once a child turns 18, the young person is in charge of his or her educational and other decisions, unless the parents or another person(s) have quardianship.

Transition services are intended to prepare students to make the change from the world of school to the world of adulthood. They are a coordinated set of activities that are based on an individual transition assessment that identifies the student's needs, preferences, and interests. The results of the assessment are used in the development of the student's transition IEP post-secondary goals, transition services, course of study, and annual goals.

Post-secondary goals are required in the areas of education/ training and career/employment. The decision as to whether or not to include goals in the area of independent living skills rests with the IEP Team. Any goal written must be realistic, relevant, and measurable. The plan can be modified as a student's interests change over time.

# **Medicaid Eligibility Based on Income for Young Adults**

Young Vermont residents under age 21, with or without special needs, can receive Medicaid and EPSDT benefits if their income and resources are below a certain amount. If a young person is living with parents, the income and resources of the parents are considered to be available to the youth. Income limits are based on household size.

The income test is not absolute. If a young person whose income is over the limit has high medical expenses, he/she is allowed to "spend down" the extra money on medical costs and become eligible. After turning 18, a young adult who meets the definition of "disabled" under Social Security Rules for adults may live at home without the parents' income and resources being considered for SSI and Medicaid eligibility purposes.

# **Other Vermont Health Insurance Programs Based on Income for Young Adults**

#### **VERMONT HEALTH ACCESS PLAN (VHAP)**

VHAP is a health insurance program for low-income uninsured adults age 18 and older who have been uninsured for 12 months or more or have recently lost their insurance because of a life change such as a divorce or loss of a job.

#### **CATAMOUNT HEALTH**

Catamount Health provides comprehensive, quality health coverage at a reasonable cost, no matter how much you earn. You may also get help paying your premiums based on your income. It is designed for Vermonters age 18 or older and families who are not eligible for other state programs such as Medicaid, Medicare, or Vermont Health Access Plan and who have been uninsured for 12 months or more or have recently lost their insurance because of a life change such as a divorce or loss of a job. It is offered by Blue Cross Blue Shield of Vermont and MVP Health Care, in cooperation with the State of Vermont.

In general, Medicaid is better coverage than other government sponsored programs because:

- · Medicaid coverage for children provides more comprehensive Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits up until age 21, while Catamount or VHAP provide fewer benefits and services. Youth with multiple needs may be much better served on Medicaid.
- Catamount and VHAP Programs have premiums while Medicaid does not.
- College students can continue to receive Medicaid, while those on VHAP are terminated if there is a college plan available, even if the plan provides coverage that is inferior to VHAP. There may also be a work requirement.

# **Medicaid Access Based on Disability for Young Adults**

Young Vermont residents with disabilities and chronic conditions may be eligible for Medicaid adult services because of that disability or condition.

#### **ADULT DEVELOPMENTAL SERVICES WAIVER**

Developmental disability services refer to a variety of programs and services for individuals with developmental disabilities, including eligible adults. In Vermont, developmental services (DS) are provided by 15 different private organizations, including the 10 designated agencies represented in each geographic region of the state plus five specialized agencies. The provider agencies are non-profit organizations which contract directly with the state of Vermont Agency of Human Services.

Eligibility for adult services for individuals with developmental disabilities differs from special education eligibility. Not all individuals with developmental disabilities who are on IEPs will be eligible for developmental disability services as adults.

Eligibility for developmental services is determined during the intake process with the designated agency. To be eligible for developmental services as an adult, the individual must have: an IQ of 70 or below or a diagnosis of autism spectrum disorder (regardless of IQ), and; substantial deficits in adaptive behavior which occurred before age 18.

Once a person is found eligible, the next step is to determine whether the individual meets a funding priority. Funding priorities are determined by the state System of Care plan. Individuals who are eligible for developmental services and meet a funding priority must also be Medicaid-eligible to receive services. The actual services that will be provided will depend on the needs of the individual and will be determined annually, much like an IEP in the school setting.

For planning purposes, it is advisable to contact the intake coordinator at your local designated agency by the beginning of your child's senior year, even if the plan is for your child to continue in school until age 22. Young adults who qualify for developmental services and are approaching the end of their school life should also have a member of the designated agency as part of their transition team.

#### **ADULT MENTAL HEALTH SERVICES**

Adult mental health services through Medicaid are also available but may look different than what your child received at an earlier age. If your transition-age child has a diagnosed major mental illness (e.g., bipolar, depression, schizophrenia) that has a significant and long-term impact on his or her ability to work or live independently, he or she may be eligible for the Community Rehabilitation and Treatment (CRT) Program. Make an appointment with the designated agency in your area to discuss eligibility and other possible sources of support.

#### **CHOICES FOR CARE**

Adult Vermonters who need long-term care services either in their home or a nursing facility may qualify for financial assistance through the Department of Disabilities, Aging and Independent Living Choices for Care Program. This Medicaid funded, long-term care program pays for care and support for older Vermonters and people with physical disabilities. The

program assists people with activities of daily living such as bathing, dressing, and mobility in an enhanced residential care setting or in a nursing facility. More details on this program were previously described in Chapter 3.

#### HIGH TECHNOLOGY HOME CARE PROGRAM

The High Technology Home Care Program may continue to be available to children after age 18. See Chapter 4 for more detail on this program.

#### **Medicare**

Medicare is a federal health insurance program for people age 65 and over, people under age 65 who are disabled, and individuals with permanent kidney failure that requires regular dialysis or a kidney transplant. It is not common for children to be covered by Medicare, as Medicaid EPSDT generally provides better benefits for children under age 21. However, depending on which of the six ways a child with a disability or chronic condition was eligible for Medicaid before adulthood, Medicare may become a better option after age 18. Medicare has four parts.

#### **FOUR PARTS OF MEDICARE**

**PART A** (hospital insurance) helps pays for inpatient hospital care, outpatient or inpatient care at critical care hospitals, skilled nursing facilities, and hospice care.

PART B (medical insurance) helps pay for doctor services, outpatient hospital care, and some physical and occupational therapists.

PART C (Medicare Advantage Plans) is a plan choice you may have as part of Medicare. They are offered by private companies approved by Medicare. If you join a Medicare Advantage Plan, the plan will provide all of your Part A (Hospital Insurance) and Part B (Medical Insurance) coverage.

**PART D** of Medicare provides insurance for prescription drugs. Different drug plans have different benefits, premiums, deductibles, coinsurance, and co-payments.

Most people do not pay for Medicare Part A because they paid the Medicare tax when they were working. Most people pay monthly for Part B or Part C. Part D costs depend on the plan you choose. People with Medicare coverage may be eligible to have some of these premiums paid by Medicaid. (See next section on **Dual Eligibility.**)

# **Medicare/Medicaid Dual Eligibility**

Elders and people with disabilities who have lower incomes and who are receiving Medicare could also qualify for Medicaid benefits. This is called being dual eligible. This allows the state Medicaid program to pay some of the costs of Medicare, such as Medicare premiums and the cost of additional health services and prescriptions.

Individuals who are dual eligible tend to be among the most medically and financially challenged beneficiaries of Medicare or Medicaid. More than two thirds of dual eligible program expenditures are for long-term care services.

Unfortunately, lack of connection between the two payors and differences in reimbursement can lead to confusion about coverage and benefits and difficulties in claims processing. The State of Vermont is currently developing a new approach to integrate health care for individuals who are eligible for both Medicare and Medicaid.

# Summary

Transition to adulthood poses a new set of challenges in accessing health care services for your young adult, and for you as a parent. Just as with children, there are a myriad of programs that may or may not be available to your child. Vermont Family Network can help.

Please contact Vermont Family Network at 1-800-800-4005 / www.VermontFamilyNetwork.org if you want more information or support about these topics.

# **Appendix A:** Glossary

**Activities of Daily Living (ADLs):** Often the criteria to qualify for certain services, these include bathing, dressing, eating, mobility, transferring, toileting and grooming.

Affordable Care Act (ACA): The Patient Protection and Affordable Care Act (PPACA) or Affordable Care Act is the federal health reform legislation signed into law in March 2010. Extends coverage to many uninsured Americans, attempts to lower health care costs and improve efficiency, and eliminates industry practices that contribute to denial of coverage.

**Allowed Charge:** The amount an insurer will allow the provider to charge for each service.

**Annual Limit:** The total amount the insurer will pay over the course of a plan year.

Annual Out-of-Pocket Maximum: The most an insured person will have to pay in any given year for all services received under an insurance policy. This amount includes co-payments and deductibles.

Balance Billing: The portion of charges the insured person is billed after the insurance company pays the usual and customary or allowed charges it deems appropriate for the services received, after the insured pays co-payments or coinsurance.

Beneficiary: The person enrolled in a health insurance plan who receives insurance benefits.

**Capitation:** A fixed sum that an insurer pays to a health plan or provider for each person served, regardless of how much services are used.

**Carrier:** The insurance company or HMO offering a health plan.

**Case Management:** A system of review and coordination to ensure that individuals receive appropriate, reasonable health care services.

#### **Children with Special Health Care Needs (CSHCN or CYSHCN):**

Defined by the Maternal and Child Health Bureau as children from birth to age 21 who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and need health and related services of a type or amount beyond that required by children generally.

Children's Health Insurance Program (CHIP): Provides coverage to low- and moderate-income children. Like Medicaid, it is jointly funded and administered by the states and the federal government. It was originally called the State Children's Health Insurance Program (SCHIP).

**COBRA:** This law (Consolidated Omnibus Budget Reconciliation Act) allows employees and their dependents who previously had health insurance through their employer to purchase and continue coverage for a limited time period.

**Coinsurance:** An insured person's share of the health care provider's charge, usually a percentage of the charge. Coinsurance is often split 80%-20%.

Community Rating: A way of pricing insurance where every policyholder pays the same premium, regardless of health status, age, or other factors

**Coordination of Benefits (COB):** A provision in a health insurance policy that applies when a person is covered under more than one medical program to eliminate over-insurance and duplication. COB provisions determine which insurer pays first and the amount each pays.

Co-payment (or Co-pay): The set dollar amount (often \$10 or \$20) which a patient must pay when visiting a health care provider. Insurance pays the rest of the fee.

**Cost-sharing:** Health care provider charges for which a patient is responsible under the terms of a health plan. Cost-sharing includes deductibles, coinsurance and co-payments. Balance-billed charges from out-of-network physicians are not considered cost-sharing.

**Deductible:** A dollar amount that a patient must pay for health care services each year before the insurer will begin paying claims under a policy. A policy may contain a deductible that applies to each covered member and a limit on the total amount of deductible a family will pay.

**Dependent:** An individual (usually a child or a spouse) who relies on another person for support and who obtains health coverage through that person.

**Employee Assistance Program (EAP):** Counseling services that are sometimes offered by insurance companies or employers. Typically, individuals or employers do not have to directly pay for services provided through an employee assistance program.

**Employer-Sponsored Health Plans:** These plans are purchased by employers to provide health insurance for their workers. This is the most common way that Americans access private health insurance plans.

ERISA: The Employee Retirement Income Security Act of 1974 regulates employee benefits, including health care benefits.

**Exchange:** Federal health care reform calls for the creation of health benefit exchanges in each state to assist individuals and small businesses in comparing and purchasing qualified health insurance plans. Each exchange will determine who qualifies for subsidies and make subsidy payments to insurers on behalf of the individuals receiving them. Exchanges will also accept applications for other health coverage programs such as Medicaid and CHIP.

**Exclusions:** Specific conditions or circumstances listed in an insurance policy that eliminate coverage for certain types of health condition or situations.

**Explanation of Benefits (EOB):** The insurance company's written explanation of a claim that shows what they paid and what the client must pay. The EOB is sometimes accompanied by a benefits check. The EOB shows the services provided, the amount billed, the insurance company payment made, and the insured person's out-of-pocket responsibility (deductible, coinsurance and/or co-payments) or an explanation of the denial of benefits.

Fee-for-Service: A system of health insurance payment in which a doctor or other health care provider is paid for each particular service provided. This is the traditional health care payment system used in indemnity insurance. Beneficiaries usually may choose to go to any provider they want, as long as the provider is willing to accept the insurance company's payments.

**Formulary:** The list of drugs covered fully or in part by a health plan.

**Generic Drug:** Once a company's patent on a brand-name prescription drug has expired, other drug companies are allowed to sell the same drug under its' chemical name or functional description. Generic drugs are less expensive and most prescription and health plans reward clients for choosing generic drugs.

**Group Health Insurance:** Coverage through an employer or employee organization (like a union) that that provides medical care for all participants in the group and/or their dependents. Coverage can be direct, though insurance, by reimbursement, or in other ways.

**Grace Period:** The period of time after a premium becomes due in which you can still pay for the insurance and keep it in force. Vermont law requires health insurers to give written notice at least 14 days before canceling a policy because you failed to make the payment by the regular due date.

**Guaranteed Renewability:** A requirement that health insurers renew coverage under a health plan unless the insured has failed to pay the premium or in cases of fraud. HIPAA requires that all health insurance be guaranteed renewable.

Health Maintenance Organization (HMO): A type of managed care organization (health plan) that provides health care coverage through a network of hospitals, doctors and other health care providers. Most services are provided by physicians who are employed by, or under contract with, the HMO. The monthly fees remain the same, regardless of types or levels of services provided.

Health Savings Account (HAS): A tax-exempt trust or custodial savings account set up to pay for qualified medical expenses for beneficiaries covered under a high deductible health plan. HSAs are individually owned and portable, like an IRA.

High Deductible Health Plan: A plan that requires greater out-ofpocket spending although premiums may be lower. This plan may not be a good option for persons with disabilities or chronic conditions who are frequent users of health care.

**High Risk Pool:** A state-subsidized health plan that provides coverage for individuals with pre-existing health care conditions who cannot purchase it in the private market.

HIPAA: This federal law (Health Insurance Portability and Accountability Act of 1996) made it easier for individuals to move from job to job without losing insurance or coverage. It also mandated standards for the electronic exchange of health care data; the use of national identification systems for patients, providers, payors, and employers (or sponsors), and required measures to protect the security and privacy of patients.

Home and Community Based Waiver: A Medicaid waiver that permits a state to offer a wide array of services that an individual may need to avoid more costly institutional care.

**In-Network Provider:** A health care provider (such as a hospital or doctor) that has contracted to be part of the network for a managed care organization or insurance plan, usually for discounted payment. The provider agrees to the rules and fee schedules in order to be part of the network and agrees not to balance bill patients for amounts beyond the agreed upon fee.

**Indemnity Plan:** A system of health insurance payment in which a doctor or other health care provider is paid for each particular service rendered. (See fee-for-service.) This type of insurance allows more freedom to choose providers and usually requires members to pay certain out-of-pocket costs such as deductibles and coinsurance for covered medical expenses.

**Individual Coverage:** Health insurance bought directly by an individual not eligible for group coverage through an employer or association (also called non-group or self-pay coverage).

Katie Beckett Program: Allows children with complex health needs (that could require hospital or institutional care) to be cared for at home with services paid by Medicaid. Parent income is not counted for eligibility.

Lifetime Benefit Maximum (or Lifetime Limit or Maximum Lifetime **Benefit):** The maximum amount a health plan will pay over the course of an individual's life. Federal health care reform now prohibits lifetime limits on benefits.

Limited Benefits Plan: A type of health plan that provides coverage only for certain specified health care services or treatments or provides coverage for health care services or treatments only for a certain amount during a specified period.

Long-Term Care Insurance: This type of insurance is designed to help pay for some or all long-term care costs, including care in a nursing home, adult day care facility or at home. Benefits are paid when the insured person needs assistance with activities of daily living, or suffers from a cognitive impairment.

Managed Care: A system that manages care delivery to control costs and coordinate services. The system often requires members to choose a primary care provider, to obtain the primary care provider's permission to see a specialist, and to use providers within the plan's network.

Mandated Benefits: Benefits that health insurance plans are required by state or federal law to provide to policyholders and eligible dependents.

Medicaid: A jointly funded state and federal program, administered by the states, that provides health insurance to certain eligible people. Eligibility for Medicaid is based on income, disability, and/or other criteria.

Medicare: A federally funded health insurance program, administered by the federal government, for people 65 years of age and older, certain younger people with disabilities, and people with end stage renal disease.

Medicare Supplemental (Medigap) Insurance: Private insurance policies that can be purchased by Medicare recipients to "fill in the gaps" not covered by Medicare and/or pay for certain out-of-pocket expenses like deductibles and coinsurance.

**Network:** The group of physicians, hospitals and other providers who contract with an insurance company to provide services to members.

**Open Enrollment Period:** A specified period during which individuals may enroll in a health insurance plan each year. In certain situations (for example a birth, death or divorce in the family) individuals may be allowed to enroll in a plan outside of the open enrollment period.

Out-of-Network: Provider Any provider, hospital, pharmacy or other facility that has not contracted with the health insurance plan to provide services to the plan's members. An individual may not be c overed at all, or may be required to pay a higher portion of the total costs, if he or she seeks care from an out-of-network provider.

Out-of-Pocket Limit: An annual limitation on all cost-sharing for which patients are responsible under a health insurance plan. This limit does not apply to premiums, balance-billed charges from out of network health care providers, or services that are not covered by the plan.

Palliative Care: Care focused on quality of life for patients with progressive, incurable illness.

Participating Provider: Provider who has agreed to accept a certain level of payment from an indemnity plan for treating a person insured by the plan. Beneficiaries may not be required to use participating providers, but often pay more if they do not.

Patient Protection and Affordable Care Act (PPACA): See Affordable Care Act

**Pre-Existing Condition:** Exclusion A contractual limitation or exclusion of benefits for an illness, medical condition, or injury that was recognized, diagnosed, or treated before buying a new health care policy. The ACA prohibits pre-existing condition exclusions for all plans beginning January 2014.

Preferred Provider Organizations (PPO): A type of managed care organization or plan that provides health care coverage through a network of providers. The PPO usually requires the policyholder to pay higher costs when care is provided by an out-of-network provider.

**Premium:** The amount paid to an insurance company in exchange for providing coverage for a specified period of time under a contract. Premiums are usually paid monthly, but can be charged on an annual or quarterly basis.

Preventative Benefits: Covered services that are intended to prevent disease or to identify disease while it is more easily treatable. The ACA requires insurers to provide coverage for preventative benefits without deductibles, co-payments, or coinsurance.

Primary Care Provider (PCP): The health care provider a managed care plan's member is required to contact first when he or she needs health care services, usually a physician specializing in primary care services. The PCP is responsible for knowing the member's complete medical history, performing routine health care, referring the member to a specialist when necessary.

Prior Authorization: A requirement that an insured obtain the plan's approval for certain services before the service can be received and paid for by the company.

Provider: The term used for health professionals such as doctors, hospitals, nurse practitioners, chiropractors, physical therapists, and others offering health care services.

**Private Health Insurance:** These are insurance plans marketed by the private health insurance industry. Most plans are for employees with employer-sponsored insurance benefits, but other groups and individuals may also buy private health insurance.

Reasonable and Customary Charge: A charge for health care based on the going rate in a certain geographic area for identical or similar services. This may also be referred to as usual and customary charge or allowed price.

Referral: An authorization given by a provider, usually a primary care provider, allowing a managed care plan member to seek care from a specialist.

**Rider:** Optional coverage for benefits not covered in a basic policy and purchased for an additional premium. Some of the more common riders cover benefits like prescription drugs, vision, dental care, or durable medical equipment.

**Second Opinion:** A medical opinion provided by a second physician or medical expert, after one physician provides a diagnosis for a serious condition or recommends surgery.

Self-Insured (Self-Funded) Plan: A health insurance plan provided by an employer who assumes all of the financial risk of providing health insurance benefits to employees. In some cases the employer will hire an independent manager or insurance company to handle claim processing and other administrative duties.

Single-Payor (Payer) System: A health care system in which one entity collects all health care fees and pays for all health care costs for the purpose of reducing complexity, paperwork, and administrative waste. A single-payor system is not the same as socialized medicine. Under a single-payor system, health care providers do not work for the singlepayor entity and patients have freedom to choose providers.

**Subscriber:** The person responsible for payment of premiums or whose employment is the basis for eligibility for membership in a health plan.

Usual, Customary and Reasonable charge (UCR): The cost associated with a health care service that is consistent with the going rate for identical or similar services within a particular geographic area. Reimbursement for out-of-network providers is often set at a percentage of the usual, customary and reasonable charge, which may differ from what the provider actually charges for the service.

Waiting Period: Set periods of time that an employer may make a new employee wait before enrolling in the company's health care plan. The health insurance policy cannot impose a waiting period, but the employer may.

# Appendix B: Acronyms

AAA	Area Agency on Aging			
AABD	Aid to the Aged, Blind & Disabled			
AAG	Assistant Attorney General			
AAP	American Academy of Pediatrics			
ABD	Aged, Blind and Disabled			
ACA	Affordable Care Act			
ACCESS	The computer software system used by DCF and DVHA to track program eligibility information			
ADAP	Alcohol and Drug Abuse Programs			
AEP	Annual Enrollment Period			
AHCPR	Agency for Health Care Policy & Research			
AHEC	Area Health Education Center			
AHRQ	Agency for Healthcare Research & Quality			
AHS	Agency of Human Services			
AIM	Advanced Information Management system			
AMA	American Medical Association			
ANFC	Aid to Needy Families with Children			
APA	Administrative Procedures Act			
ARIS	ARIS Solutions: Fiscal Agent and Non-Profit Financial Services			
AWP	Average Wholesale Price			
BIA	Brain Injury Association of Vermont			
BC/BS	Blue Cross/Blue Shield			
BD	Blind & Disabled			
BISHCA	Banking, Insurance, Securities, & Health Care Administration (Department of)			
CAP	Community Action Program			
CDCI	Center on Disability and Community Inclusion			
CFC	Choices for Care			
CHAP	Catamount Health Assistance Program			
CHF	Congestive Heart Failure			
CHIPRA	Children's Health Insurance Program Re-authorization Act of 2009			
CHPR	Center for Health Policy and Research			
CIS	Children's Integrated Services			
CIS-EI	Children's Integrated Services – Early Intervention (Part C of IDEA)			

CM	Case Management			
CMN	Certification of Medical Necessity			
CMS	Centers for Medicare & Medicaid Services (formerly HCFA)			
CMSO	Center for Medicaid & State Operations			
COA	Council on Aging			
СОВ	Coordination of Benefits			
CON	Certificate of Need			
cos	Categories of Service			
СРН	Community Public Health (of the VDH)			
CSP	Coordinated Services Plan			
CRT	Community Rehabilitation & Treatment			
CSHN	Children with Special Health Needs			
DA	Designated Agency			
DAIL	Department of Disabilities, Aging, and Independent Living			
DCF	Department for Children and Families			
DCHC	Disabled Children's Home Care			
DDS	Disability Determination Services (part of DCF)			
DHHS	Department of Health & Human Services (United States)			
DME	Durable Medical Equipment			
DMH	Department of Mental Health			
DO	District Office			
DOB	Date of Birth			
DR. D	Dr. Dynasaur Program			
DRG	Diagnosis Related Grouping			
DS	Developmental Services			
DSH	Disproportionate Share Hospital			
DUR	Drug Utilization Review (Board)			
DVHA	Department of Vermont Health Access			
EEE	Essential Early Education			
EOMB	Explanation of Medicare (or Medicaid) Benefits			
EPSDT	Early Periodic Screening, Diagnosis & Treatment			
ER	Emergency Room			
ESD	Economic Services Division (of the DCF)			
ESI	Employer Sponsored Insurance			
FAPE	Free, Appropriate Public Education			

FMAP	Federal Medical Assistance Percentage			
FPL	Federal Poverty Level			
FQHC	Federally Qualified Health Centers			
GAO	General Accounting Office			
GMC	Green Mountain Care			
GMSA	Green Mountain Self Advocates			
HAEU	Health Access Eligibility Unit			
HCBS	Home and Community-Based Services			
HCFA	Health Care Finance Administration (now CMS)			
ННА	Home Health Agency			
HHS	Health and Human Services (U.S. Department of)			
HIPAA	Health Insurance Portability & Accountability Act			
HRSA	Health Resources and Services Administration			
HSB	Human Services Board			
ICU	Intensive Care Unit			
ID	Identification			
	The Individuals with Disabilities in Education Act			
IDEA	Individuals with Disabilities in Education Act  Individualized Education Plan			
IEP				
IFSP 	Individualized Family Service Plan			
IT	Information Technology			
LEA	Local Education Agency			
LIHEAP	Low-Income Home Energy Assistance Program			
LIT	Local Interagency Team			
LTC	Long-Term Care			
MAB	Medicaid Advisory Board			
MAC	Maximum Allowable Cost (refers for drug pricing)			
MARS	Management & Administrative Reporting			
МСО	Managed Care Organization			
MCP	Managed Care Plan			
MFRAU	Medicaid Fraud & Residential Abuse Unit			
MIS	Management Information System			
MMA	Medicare Modernization Act			
MMIS	Medicaid Management Information System			
MNF	Medical Necessity Form			
MOE	Maintenance of Effort			
MVP	Mohawk Valley Physicians			
OEO	Office of Economic Opportunity			
отс	Over the Counter			
PA	Prior Authorization or Public Assistance			
PACE	Program for All-Inclusive Care for the Elderly			
PCA	Personal Care Assistant			
PC Plus	VT Primary Care Plus			
PCP	Primary Care Provider			
PDL	Preferred Drug List			
РНО	Physician Hospital Organization			
PI	Program Integrity			
PMPM	Per Member Per Month			
	. cc. r cr monar			

RN	Registered Nurse		
RU			
	Reach Up program		
SCHIP	Substance Abuse & Mental Health Services Administration State Children's Health Insurance Program		
SIT	J		
SNF	State Interagency Team Chilled Number 75 ediling		
	Skilled Nursing Facility		
SPAP	State Pharmacy Assistance Program		
SSA	Social Security Administration		
SSI	Supplemental Security Income		
SSN	Social Security Number		
SUR	Surveillance & Utilization Review		
TANF	Temporary Assistance for Needy Families (Reach Up in VT)		
ТВІ	Traumatic Brain Injury		
UCR	Usual & Customary Rate		
UR	Utilization Review		
VA	Veteran's Administration		
VABVI	VT Association for the Blind & Visually Impaired		
VAHHA	VT Assembly of Home Health Agencies		
VAHHS	VT Association of Hospital & Health Systems		
VCCI	VT Chronic Care Initiative		
VDH	VT Department of Health		
VCDR	Vermont Coalition for Disability Rights		
VFF	Vermont Federation of Families for Children's Mental Health		
VHAP	VT Health Access Plan		
VHAP-Rx	VT Health Access Plan Pharmacy Program		
VLA	VT Legal Aid		
VMS	VT Medical Society		
VNA	VT Nurses Association		
VPA	Vermont Protection & Advocacy		
VPHARM	VT Pharmacy Program		
VPQHC	VT Program for Quality in Health Care		
VPTA	Vermont Public Transportation Agency		
VR	Vocational Rehabilitation		
VScript	VT Pharmacy Assistance Program		
VSDS	VT State Dental Society		
VSH	VT State Hospital		
VT	State of Vermont		
VTAD	Vermont Association for the Deaf (and Hard of Hearing)		
WIC	Women, Infants, & Children		
wtw	Welfare to Work		

# **Appendix C: Useful Resources and Contact Information**

#### **USEFUL PUBLICATIONS**

Copies of these publications are available at Vermont Family Network or direct from the publishing organization.

Health Care Programs Handbook **Department of Vermont Health Access** 1-800-250-8427 TTY 1-888-834-7898 www.greenmountaincare.org

The Vermont Parents' Home Companion Prevent Child Abuse Vermont PO Box 829 Montpelier, VT 05601 1-800-CHILDREN (1-800-244-5373) www.pcavt.org

Overview of Green Mountain Care Programs Office of Health Care Ombudsman 1-800-917-7787 www.vtlawhelp.org/node/252

A Consumer's Guide to Health Insurance Vermont Department of Banking, Insurance, Securities and Health Care Administration 89 Main Street Montpelier, VT 05620-3101 1-800-631-7788 TTY 1-800-253-0191 www.bishca.state.vt.us

#### STATEWIDE ORGANIZATIONS AND AGENCIES

#### Banking, Insurance, Securities and Health Care Administration (BISHCA)

Promotes and assures the financial health, stability, quality and integrity of Vermont financial service providers and health care entities.

89 Main Street Montpelier, VT 05620-3101 (802) 828-3301 www.bishca.state.vt.us

#### **Children with Special Health Care Needs** (CSHN), Vermont Department of Health (VDH)

CSHN provides comprehensive, family-centered services to children aged birth to 21 with chronic or disabling conditions, including developmental and behavioral delays.

108 Cherry Street Burlington, VT 05402 1-800-660-4427 Fax: (802) 865-7754

http://healthvermont.gov/family/cshn

#### Department of Disabilities, Aging & Independent Living (DAIL)

DAIL is part of the Agency of Human Services and provides a variety of services to Vermonters who are over the age of 60 or who have a disability.

(802) 241-2401 http://dail.vermont.gov

#### **Department of Mental Health (DMH)**

As part of the Agency of Human Services, DMH works to promote and improve the mental health of Vermonters. DMH supports a network of community mental health centers known as Designated Agencies who provide service to adults and children.

(802) 828-3824 http://mentalhealth.vermont.gov

#### **Department of Vermont Health Access** (DVHA)

Assists Medicaid beneficiaries in accessing clinically appropriate health services, and administers Vermont's public health insurance system.

312 Hurricane Lane, Suite 201 Williston, VT 05495 (802) 879-5900 http://ovha.vermont.gov

#### **Economic Services Division, Department for Children and Families (DCF)**

As part of the Vermont Agency of Human Services' Department for Children and Families, Economic Services Division (ESD) helps Vermonters meet their basic needs through programs such as 3SquaresVT, Essential Person, Fuel Assistance, and Reach Up.

1-800-479-6151 http://dcf.vermont.gov/esd

#### **Field Services Division, Vermont Agency of Human Services**

AHS Field Directors work to ensure that all individuals and families involved with multiple programs have holistic plans and wellcoordinated services.

1-800-871-3009 http://humanservices.vermont.gov/ departments/ahs-fs-folder/

#### Office of Health Care Ombudsman

Provides help to Vermonters that have problems and questions about health care and health insurance through a telephone hotline service. 1-800-917-7787

www.vtlegalaid.org/office-of-health-careombudsman

#### **LOCAL MENTAL HEALTH AGENCIES**

#### **Transition II, Inc.**

Provides support and employment for people with disabilities. 346 Shelburne Road Burlington, VT 05401 (802) 846-7007 or 1-866-572-7127

Fax: (802) 846-7282 www.transitionii.com

#### Vermont 2-1-1

The Vermont 2-1-1 center is available 24 hours a day/seven days a week for statewide information, referral and assistance on a variety of topics.

PO Box 111 Essex Junction, VT 05453 211 Fax: (802) 861-2544 info@vermont211.org

www.vermont211.org

#### **Vermont Family Network (VFN)**

Vermont Family Network is a non-profit organization that promotes better health. education, and well-being for all children and families, with a focus on children and young adults with special needs.

600 Blair Park Road, Suite 240 Williston, VT 05495 1-800-800-4005 www.vermontfamilynetwork.org

#### **Vermont Federation of Families for Children's Mental Health**

Supports families with a child experiencing emotional, behavioral, or mental challenges.

600 Blair Park Road PO Box 1577 Williston, VT 05495 (802) 876-7021 1-800-639-6071

#### **Vermont Legal Aid**

Helps provide legal support for people who are poor, ederly, or have disabilities. 264 North Winooski Avenue PO Box 1367 Burlington, VT 05402 1-800-899-2047 www.vtlegalaid.org/office-of-health-careombudsman

These are Designated Agencies for the Vermont Department of Mental Health, and provide mental health supports and services to Vermont's adults and children in their communities.

#### **Clara Martin Center**

Serving Orange County: Including Bethel, Granville, Hancock, Rochester, Royalton, Sharon and Stockbridge 11 Main Street, Box G Randolph, VT 05060 1-800-639-6320 Fax: (802) 728-4197 www.claramartin.org

#### **Counseling Service of Addison County**

Serving Addison County 89 Main Street Middlebury, VT 05753 (802) 388-6751 Fax: (802) 388-3108 www.csac-vt.org

#### **Health Care and Rehabilitation Services of Southeastern Vermont**

Serving Windham and Windsor Counties 1 Hospital Court, Suite 410 Bellows Falls, VT 05101 (802) 463-3947 Fax: (802) 463-1202 www.hcrs.org

#### **Lamoille Community Connections**

Serving Lamoille County 72 Harrel Street Morrisville, VT 05661 (802) 888-5206 Fax: (802)888-6393

#### **Howard Center**

Serving Chittenden County 300 Flynn Avenue Burlington, VT 05401 (802) 660-3678 Fax: (802) 865-6117 www.howardcenter.org

#### **Northeast Kingdom Human Services**

Serving Caledonia, Essex and Orleans Counties PO Box 724 154 Duchess Street Newport, VT 05855-0724 (802) 334-6744 Fax: (802) 334-7455 www.nkhs.net

#### **Northwestern Counseling and Support Services**

Serving Franklin and Grand Isle Counties 107 Fisher Pond Road St. Albans, VT 05478 (802) 524-6554 or 1-800-834-7793 Fax: (802) 527-7801 www.ncssinc.org

#### **Rutland Mental Health Services, Inc.**

Serving Rutland County 78 South Main Street PO Box 222 Rutland, VT 05701 (802) 775-2381 Fax: (802) 775-3307 www.rmhsccn.org

#### **United Counseling Service, Inc.**

Serving Bennington County 1 Ledge Hill Drive PO Box 588 Bennington, VT 05201 (802) 442-5491 Fax: (802) 442-3363 www.ucsvt.org

#### **Washington County Mental Health Services, Inc.**

Serving Washington County PO Box 647 Montpelier, VT 05601-0647 (802) 229-0591 www.wcmhs.org

#### **Northeastern Family Institute (NFI)**

Serving Burlington, South Burlington, Barton, Brattleboro, Caledonia, Hardwick, Hartford, Newport, St. Albans, St. Johnsbury, Springfield, Williston and Winooski Administration Office: (802) 658-0040 http://nfivt.org

#### **LOCAL DEVELOPMENTAL SERVICES (DS) AGENCIES**

Developmental disability services assist children, adolescent, and adults who have a qualifying developmental disability to live, attend school, work, and recreate in their communities. Supports are provided to over 3,000 people by private non-profit developmental disability services providers throughout the state.

#### **Upper Valley Services, Inc. (UVS)**

Serving Orange County 267 Waits River Road Bradford, VT 05033 (802) 222-9235

Emergency Services: (802) 222-9235 After hours (Clara Martin Center):

1-800-639-6360 Fax: (802) 222-5864 www.arearesource.org

# **Counseling Service of Addison County**

Serving Addison County **Community Associates** 109 Catamount Park Middlebury, VT 05753 (802) 388-4021 Emergency Services: (802) 388-7641

Fax: (802) 388-1868 www.csac-vt.org

#### **Specialized Community Care, Inc. (SCC)**

Serving Addison and Rutland Counties PO Box 578

East Middlebury, VT 05740

Physical Location: 3627 Route 7 South

(802) 388-6388 Fax: (802) 388-6704

#### **Health Care and Rehabilitation Services of Southeastern Vermont**

Serving Windsor and Windham Counties 12 Church Street Bellows Falls, VT 05101 (802) 463-3962 Emergency Services: 1-800-622-4235

Fax: (802) 463-3961 www.hcrs.org

#### **Lincoln Street Incorporated**

Serving Windsor and Windham Counties PO Box 678 374 River Street Springfield, VT 05156 (802) 886-1833 Fax: (802) 886-1835 www.lincolnstreetinc.org

#### **Families First**

Serving Windham County PO Box 939 Wilmington, VT 05363 (802) 464-9633 Fax: (802)464-3173 www.familiesfirstvt.com

#### **Lamoille Community Connections**

Serving Lamoille County 72 Harrel Street Morrisville, VT 05661 (802) 888-5206

Emergency Services: (802) 888-6627; After hours: (802) 283-0957

Fax: (802) 888-6393

#### **Howard Center**

Serving Chittenden County 102 South Winooski Avenue Burlington, VT 05401 (802) 488-6500 Emergency Services: (802) 488-6400 Fax: (802) 488-6501 www.howardcenter.org

#### Northeast Kingdom Human Services (NKHS)

Serving Caledonia, Essex and Orleans Counties PO Box 724 154 Duchess Street Newport, VT 05855-0724 (802) 334-7310 Emergency Services: (802) 334-6744

Fax: (802) 334-7455 www.nkhs.net

#### **Northwestern Counseling and Support** Services (NCSS)

Serving Franklin and Grand Isle Counties 107 Fisher Pond Road St. Albans, VT 05478 (802) 524-6554 or 1-800-834-7793 Fax: (802) 527-7801

www.ncssinc.org

#### **Rutland Mental Health Services, Inc.**

Serving Rutland County PO Box 222 78 South Main Street Rutland, VT 05701 (802) 775-2381 Fax: (802) 775-3307 www.rmhsccn.org

#### **United Counseling Service, Inc. (UCS)**

Serving Bennington County 100 Ledge Hill Drive PO Box 588 Bennington, VT 05201 (802) 442-5491

Emergency Services: (802) 442-5491 Developmental Services Fax: (802) 442-1705

www.ucsvt.org

#### **Community Developmental Services (CDS)**

Serving Washington County 50 Grandview Drive Barre, VT 05641 (802) 479-2502 Voice Mail: (802) 479-5012

Emergency Services: (802) 229-0591

Fax: (802) 479-4056 www.wcmhs.org

#### Sterling Area Services, Inc. (SAS)

Serving Northern and Central Vermont 109 Professional Drive Morrisville, VT 05661 (802) 888-7602 Fax: (802) 888-1182 www.sterlingarea.com

#### **Champlain Community Services, Inc. (CCS)**

Serving Chittenden and throughout northern Vermont 512 Troy Avenue, Suite #1 Colchester, VT 05446 (802) 655-0511 Fax: (802) 655-5207 www.ccs-vt.org

#### SOCIAL SECURITY OFFICES IN VERMONT

58 Pearl Street Burlington, VT 05401 (877)-840-5771

33 School Street Montpelier, VT 05602 (877) 505-4542

330 ASA Bloomer Building 88 Merchants Row Rutland, VT 05701 (866) 690-1944

National SSA Toll-Free Number: 1-800-772-1213 www.ssa.gov



600 Blair Park Road, Suite 240 Williston, VT 05495-7549 1-800-800-4005

www.VermontFamilyNetwork.org