

APPENDIX

SSI

The following appendix is compiled from information from:

A Parent's and Advocate's Handbook on How Children Can Qualify for Monthly SSI Benefits and Medicaid, 1997, Washington D.C., Judge David L. Bazelon Center for Mental Health Law.

The Advocates Guide to SSI for Children, 1998, Washington D.C., Judge David L. Bazelon Center for Mental Health Law, Mental Health Law Project.

SSI for Children website, Judge David L. Bazelon Center for Mental Health Law, Washington, DC.

Understanding SSI, Social Security Agency

Help for Children with Disabilities, Social Security Agency

APPENDIX

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WHAT IS SSI?

SSI stands for Supplemental Security Income. It is a monthly payment from the Social Security Administration (SSA) to people with limited income and resources who are over 65 years of age, blind, or disabled.

WHO IS CONSIDERED A "CHILD" BY SSA?

A person who is neither married nor head of the household and:

- is under age 18; or,
- is under age 22 and is a student regularly attending school or college or training that is designed to prepare the person for a paying job.

WHAT CAN AN ELIGIBLE CHILD RECEIVE?

- **A MONTHLY CHECK:** Effective 1/1/02, the maximum federal SSI payment for a child is \$545 per month. The exact amount a child receives depends on the family's income and living arrangements and other factors.
- **STATE SSI SUPPLEMENTS:** About half the states currently supplement the federal SSI benefit for children with an additional payment. The State of Vermont adds \$59.04 to the federal payment for a child living at home.
- **MEDICAID:** Children who receive even \$1 of SSI benefits generally qualify for Medicaid in Vermont and in 37 other states and the District of Columbia. (In seven of these states, children receiving SSI must apply for it separately.) The other 12 states use different eligibility criteria for Medicaid and SSI, although most children receiving SSI are eligible for Medicaid.

WHY A CHILD WHO IS BLIND OR DISABLED SHOULD APPLY FOR SSI:

There's a good chance the child can qualify. For example, earnings for two parents with one child with a disability living in Vermont can be up to \$2,967 per month (\$35,604 per year), with total family resources of \$5,000. Income limits are higher in larger families.

CHILDREN'S ELIGIBILITY REQUIREMENTS

1. DISABILITY OR BLINDNESS

- BLINDNESS: “Central visual acuity” of 20/200 or less in the better eye with the use of a corrective lens or a limitation in the field of vision of 20 degrees or less.
- DISABILITY DEFINITIONS FOR CHILDREN:
 - under 18, or 18-22 and a student; and,
 - if under 18, has a physical or mental condition or conditions that can be medically proven and which result in marked and severe functional limitations, or,
 - if 18-22, the adult disability definition applies, or,
 - the condition(s) must have lasted or be expected to last at least 12 months or end in death.

(See How SSA Determines Eligibility, page 44 for details.)

2. CITIZENSHIP:

- Must be a United States citizen; or
- an alien who meets the alien eligibility criteria under the 1996 legislation and its amendments.

3. RESIDENCY:

- Must live in the U.S., including the 50 states, the District of Columbia, and the Northern Mariana Islands;
- Be a child living with a parent in the military service assigned overseas to permanent duty ashore; or,
- Be a student temporarily abroad for the purpose of conducting studies.

4. LIMITED INCOME AND RESOURCES:

- INCOME LIMITS- Family income must fall within dollar limits established by regulations. SSA takes into consideration the source of the income, the number of children with and without disabilities in the household and whether or not the state in which the family lives supplements the federal SSI benefits. *(See page 40.)*
- RESOURCE LIMITS- The value of a family's resources is one of the factors that determines whether or not a person is eligible for SSI payments, but not all resources count for SSI. For a child, household resources over \$3,000 in a two-parent household, or \$2,000 for a one-parent household are counted as “deemed”, or are considered available, to the child applying for SSI. If the amount deemed to the child, combined with any resources the child has, is under \$2,000, the child may be eligible for SSI. *(See page 42.)*

APPLICATION PROCESS

SOCIAL SECURITY OFFICES

The same Social Security Administration (SSA) offices administer both the Social Security and SSI programs. SSA employees will answer questions about both programs on the telephone and in person at your local office. Informational booklets are available at all SSA offices.

CONTACTING SOCIAL SECURITY

The SSA encourages you to do business by telephone. You may contact the SSA by telephone, mail, or in person. The local phone number can be found in your local directory or on page 1 of this book.

You can get recorded information about Social Security coverage 24 hours a day, including weekends and holidays, by calling Social Security's toll-free number, **1-800-772-1213**. You can call for an appointment or to speak to a service representative between 7:00 AM and 7:00 PM, Monday through Friday. For best service, call before 9:00 AM or after 5:00 PM.

You can get SSA publications at <http://www.ssa.gov/> on the Internet.

If you are deaf or hard of hearing, you may call the toll-free TDD number, **1-800-325-0778** from 7:00 AM to 7:00 PM, on business days.

APPLYING FOR SSI

In most offices, you can make an appointment to apply for SSI by telephone or personal interview. If you are not able to make an appointment convenient for you, you may visit any SSA office. You can visit an SSA office to apply without making an appointment, but you may have to wait.

You will have to provide information and work with the SSA to get documents concerning SSI eligibility, and you will have to sign an application.

When you call or visit SSA, note the name of any staff member you speak with and the date of contact.

Put your name and Social Security number on written correspondence with SSA, and keep a copy for your records.

Most of the forms to apply for SSI are not designed for self-completion. An SSA claims representative interviews you and completes the forms with information provided by you.

APPLICANT'S CHECKLIST

SSA will ask parents for documents to support their child's SSI application. SSA needs to see the originals, not photocopies. The claims representative will copy the documents and return them.

If parents can get the documents easily, they should bring them to the application interview. But they should not put off applying while obtaining any of the documents. **It is better to apply first and bring the additional papers in later.**

THESE ARE THE MOST NEEDED DOCUMENTS:

- **SOCIAL SECURITY NUMBER.** Parents should bring the child's Social Security card or number, if the child has one. If not, SSA will help the parents get one.

- **PROOF OF AGE.** If the child doesn't yet have a Social Security number, parents will need to bring evidence of the child's age. A copy of the birth records is best; next best are religious records of birth or baptism. Other evidence can be used when these are unavailable.

- **PROOF OF CITIZENSHIP OR IMMIGRATION STATUS.** Birth certificate, green card, visa, passport, immigration, or naturalization papers are the most commonly accepted documents.

- **INFORMATION ABOUT THE CHILD'S DISABILITY OR BLINDNESS.** Parents should bring the names and addresses of doctors, hospitals, or clinics where the child has received treatment. The names and addresses of people (teachers, caregivers) who can provide information about how the child's condition affects his or her day to day activities should also be submitted. If the child has an Individualized Family Services Plan (IFSP) from an early intervention program or an Individualized Education Program (IEP) from school, the parents should bring it. Also, parents should make notes ahead of time about all the things their child can't do that other children the same age can. The more complete the medical and functional information is, the better the child's chances are to be found eligible. (See page 48.)

- **EARNED INCOME RECORDS.** If parents work for someone else, they should bring wage stubs for the present month as well as the three previous months. If they work for themselves, they should bring their federal tax return for the most recent year.

- **UNEARNED INCOME RECORDS.** Parents need to show where any unearned income (such as alimony, unemployment, worker's compensation, VA benefits or Social Security benefits) comes from, how much it is and how often they receive it. If

parents don't have the papers, SSA will usually check with the source to find out how much they receive. If the child has any income, SSA needs to know about that, too.

- **AUTO REGISTRATION.** The registration is proof of ownership. If parents use the car to get regular medical treatment or prescription drugs, they should bring appointment cards (if available) or the names of doctors or clinics. If parents have more than one car, all of the registrations are needed.

- **INFORMATION ABOUT RESOURCES.** Parents will need to provide documents that show the amount of any resources parents could turn into cash. These include bank statements for a checking account (the most recent and the previous three months), savings account passbook, savings bonds, stock certificates and life insurance policies.

DO NOT WAIT TO FILE AN APPLICATION – even if you don't have all the medical information for a 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.

HOW SOMEONE CAN HELP WITH AN SSI CLAIM

Anyone the family chooses can help by completing forms, going with the family to meetings with Social Security, interpreting, helping the family gather and give information, taking the child to medical examinations or to the SSA office and receiving mail for the child.

THE FAMILY MAY APPOINT A REPRESENTATIVE.

A representative can do all of the above plus:

- Sign an application on the child's behalf (if authorized by the parents to do so).
- Review the child's file at the Social Security office.
- Get information from SSA about the child's claim, just as the child's parents would.
- Represent the child at informal or formal hearings.
- Send evidence for the child to SSA or the Disability Determination Service (DDS).

HOW DOES THE FAMILY NAME A REPRESENTATIVE?

Parents must sign a statement naming the child's representative. The representative does not have to be an attorney.

SUGGESTIONS FOR ADVOCATES:

- **OFFER TO BE A CONTACT PERSON.** If the family consents, you may want to give your name and telephone number to the DDS disability examiner assigned to the child's case. This could speed up the disability determination process if the examiner needs additional information and cannot reach the family by telephone.
- **FOLLOW UP.** Starting about 30 days after the family has filed the application forms, either a family member or you should call the DDS to check on the status of the case. Give the child's name and Social Security number and you will be told which examiner has been assigned. Once you know the examiner's name, you can call him or her on a direct line. Ask if the examiner has been able to contact all the people on the family's list. Find out if additional information or records would help process the case. With complete and clear documentation of their disabilities,

eligible children should be able to obtain SSI benefits sooner and avoid the time an appeal takes.

- **HELP THE FAMILY RESPOND WITHIN THE STATED TIME LIMITS** – sooner, if possible – to any requests for information they receive from SSA or the DDS.
- **KEEP COPIES.** Be sure you or the family keep a copy of every document and record taken or sent to the Social Security office or the disability examiner.
- **ENCOURAGE THE FAMILY TO APPEAL IF BENEFITS ARE DENIED.** Remember, if the initial claim is denied, the family should appeal within 60 days. While it takes time, the appeals process works well, and many denials are overturned at one stage or another of the appeal. (See *page 53.*)

FINANCIAL ELIGIBILITY: INCOME

To be eligible for SSI, a child who is blind or disabled must meet income guidelines. If a child lives with parents, SSA counts part of the parents' income and resources as available to the child. This is called "deemed income".

THREE KINDS OF INCOME ARE COUNTED

Social Security will ask questions about three types of income the family might have:

- "EARNED" income – money from work, such as wages, tips, or earnings from self-employment.
- "UNEARNED" income – from non-work sources, like child support, alimony, bank interest, workers' or unemployment compensation, pensions, VA benefits, or Social Security disability benefits.
- "IN-KIND" income – food, clothing or shelter the family receives that is either free or less than the fair value.

SOME INCOME DOESN'T COUNT

Payments or services that are not counted as income for the SSI program include:

- the first \$20 of most income received in a month
- the first \$65 of earnings and one-half of earnings over \$65 received in a month
- the value of Food Stamps
- income tax refunds
- home energy assistance
- assistance based on need funded by a state or local government
- small amounts of income received irregularly or infrequently
- food, clothing, or shelter based on need provided by nonprofit agencies
- loans to you (cash or in-kind) that you have to repay
- money someone else spends to pay your expenses for items other than food, clothing, or shelter (e.g., someone pays your telephone or medical bills.)
- income set aside under a plan for achieving self-support (PASS)

Generally, the more income you have, the less your SSI payment will be. If your income is over the allowable limit, you cannot receive SSI.

INCOME ELIGIBILITY IN VERMONT 2004

The amounts below show the maximum monthly income parents may have in order for a child with disability to be eligible for at least \$1 of SSI as of January 1, 2004 (the amount changes each year to reflect inflation). The maximum levels are higher in the states that supplement SSI. The monthly limit for either type of income increases by \$282.00 for each additional child with no disability in the household.

MAXIMUM EARNED MONTHLY INCOME

Number of other children with no disability in household:	One Parent Household:	Two Parent Household:
0	\$2,485.00	\$3,049.00
1	\$2,767.00	\$3,331.00
2	\$3,049.00	\$3,613.00
3	\$3,331.00	\$3,895.00
4	\$3,613.00	\$4,177.00

MAXIMUM UNEARNED MONTHLY INCOME

Number of other children with no disability in household:	One Parent Household:	Two Parent Household:
0	\$1,220.00	\$1,502.00
1	\$1,502.00	\$1,784.00
2	\$1,784.00	\$2,066.00
3	\$2,066.00	\$2,348.00
4	\$2,348.00	\$2,630.00

If a family has both earned and unearned income, and the total amount falls between the limit for earned and unearned income, it's worth applying for SSI because the child may qualify.

Also, eligibility is calculated each month, so if your family is found ineligible, you should reapply if your income drops.

WHEN DEEMING DOES NOT APPLY

Deeming does not apply, and SSA may pay up to \$30 plus the applicable state supplement (\$17.66 in Vermont in 2001) when:

- a disabled child who received SSI while in an institution goes to live at home; and,
- the child is eligible for Medicaid under a state home care plan; and,
- deeming would otherwise cause ineligibility for SSI.

Parents whose income and/or resources would likely cause a medically eligible child to become ineligible for SSI should apply if the child meets the criteria above.

FINANCIAL ELIGIBILITY: RESOURCES

Social Security will also ask what “resources” a child and parents have. A certain portion of the parents’ resources are considered available to a child applying for SSI.

WHAT ARE RESOURCES?

Resources are things families own such as cash, bank accounts, stocks and bonds, houses, life insurance, cars or boats, land, farm equipment, furniture and personal belongings.

SOME RESOURCES DON'T COUNT

SSA excludes some resources entirely and counts the value of others only in part. Some of the resources SSA doesn’t count are:

- The family home and the land it’s on

- Personal and household belongings up to \$2,000 in value

- One wedding ring and one engagement ring

- Life insurance policies with cash or loan value up to \$1,500 (term insurance in any amount doesn’t count)

- Burial spaces for the child and his or her immediate family and burial funds valued at \$1,500 or less, if kept separated from other money

- Medical and other rehabilitation equipment

- Retroactive SSI or Social Security benefits, for up to six months after they are received

- Property needed for work, such as farm land and equipment

- One car, regardless of value, if it is:
 - necessary for employment or medical treatment; or,
 - modified for use or transportation of a disabled person; or,
 - necessary because of climate, terrain, distance or similar factors to perform essential daily activities.

(If your use of the car does not meet one of these conditions, then up to \$4,500 of its market value is excluded. The remaining value is counted against the resource limit.)

HOW MUCH CAN THE FAMILY HAVE IN RESOURCES THAT DO COUNT?

Parents may have \$3,000 in countable resources if two parents live in the 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. It’s worthwhile for parents to make a rough estimate of their countable resources. **Even if the result seems to be over the limit, the family may be able to change some of its resources into things Social Security doesn’t count.** For example, some families use cash over the resource limit to repay loans or buy a home, necessary household goods, an automobile, or term life insurance.

HOW SSA DETERMINES DISABILITY

WHAT DOES SOCIAL SECURITY LOOK FOR?

The person deciding whether your child is eligible for SSI will not see your child, but will look at information about your child's physical and mental condition. This means you should collect all the information you can to show how your child's condition interferes with his/her everyday activities. That includes medical and other written reports from doctors, nurses, therapists, child care providers, teachers, friends and family and anyone else who knows your child.

Unfortunately, getting SSI benefits depends on showing how serious your child's limitations are, even with the hard work you and your child have done and the progress you have made. You must be honest, but you need to stress the problems your child still faces every day.

NEW DEFINITION OF CHILDHOOD DISABILITY:

The SSA considers a child disabled if the physical or mental condition can be medically proven and results in "marked and severe functional limitations" of substantial duration.

HOW DOES SSA DECIDE IF A CHILD IS DISABLED?

The state agency that contracts with SSA to do SSI evaluations, called the Disability Determination Service (DDS), follows a process, called the "sequential evaluation," which is used to decide if a child meets the definition of disability. The child must meet ALL of the following criteria:

- 1) **Is the child engaged in substantial gainful activity?**
Is the child employed and making \$740 or more per month? If so, he or she must be found non-disabled. If not, the child may be eligible. If the child is a student under the age of 22 years, the SSA may exclude up to \$1290 per month or \$5200 per year in earnings and the child may still be eligible.

- 2) **Does the child have a physical or mental impairment or combination of impairments lasting at least 12 months (or resulting in death) and resulting in marked and severe functional limitations.**
If so, the child may be eligible. Social Security will view your child's records to look at the physical or mental condition as well as how your child functions in various specific areas, depending on his or her age – how he communicates, concentrates, does self-care and physical activities, and interacts with others. So when you collect information for Social Security, you should get records, reports, and letters about what your child does every day, in addition to medical records.

- 3) **Does the child’s condition appear in SSA’s “Listing of Impairments”?**
The “listing” includes descriptions of physical and mental problems, such as cerebral palsy, mental retardation, or muscular dystrophy, that are severe enough to disable a child. If the child’s condition is identical to one in the listing, does the child meet the specific criteria and level of severity required? If so, the child “meets a listing” and may be eligible.
- 4) **If the condition isn’t listed, is the child’s condition medically or functionally as serious as a listed impairment?**
If so, the child’s condition or combination of conditions “meets or equals the listing”, which means that not all the medical or functional criteria in the listing are present, but the child has other medical symptoms or functional limitations of equal severity. The child may be eligible.

If the child meets eligibility criteria in both questions 1 and 2 and either 3 or 4, your child will be considered disabled for purposes of receiving SSI.

SSA LISTING OF CHILDREN'S IMPAIRMENTS

GROWTH IMPAIRMENT MUSCULOSKELETAL SYSTEM

- Juvenile Rheumatoid Arthritis
- Deficit of Musculoskeletal Function
- Disorders of the Spine
- Chronic Osteomyelitis

RESPIRATORY SYSTEM

- Asthma
- Cystic Fibrosis
- Chronic Pulmonary Insufficiency

NEOPLASTIC DISEASES – MALIGNANT

- Lymphoreticular Malignant Neoplasms
- Malignant Solid Tumors
- Neuroblastoma
- Retinoblastoma

CARDIOVASCULAR SYSTEM

- Chronic Heart Failure
- Hypertensive Cardiovascular Disease
- Congenital Heart Disease
- Cardiac Transplantation
- Chronic Rheumatic Fever/Heart Disease
- Valvular Heart Disease or Other Stenotic Defects/Valvular Regurgitation
- Cardiomyopathies
- Hyperlipidemia
- Kawasaki Syndrome

DIGESTIVE SYSTEM

- Esophageal Obstruction
- Chronic Liver Disease
- Chronic Inflammatory Bowel Disease
- Malnutrition

ENDOCRINE SYSTEM

- Thyroid Disorders
- Diabetes Insipidus
- Hypoglycemia
- Hyperfunction of Adrenal Cortex
- Adrenal Cortical Insufficiency
- Juvenile Diabetes Mellitus
- Iatrogenic Hypercorticoid State
- Pituitary Dwarfism
- Adrenogenital Syndrome
- Hyperparathyroidism
- Hypoparathyroidism or Pseudohypo-parathyroidism
- Gonadal Dysgenesis (Turner's Syndrome)

GENITO-URINARY SYSTEM

- Chronic Renal Disease
- Nephrotic Syndrome

HEMIC and LYMPHATIC SYSTEM

- Hemolytic Anemia
- Chronic Idiopathic Thrombocytopenic Purpura
- Sickle Cell Disease
- Inherited Coagulation Disorder
- Acute Leukemia

SPECIAL SENSOR ORGANS

- Impairments of Central Visual Acuity
- Hearing Impairment

MULTIPLE BODY SYSTEMS

- Down Syndrome
- Multiple Body Dysfunction
- Catastrophic Congenital Abnormalities

NEUROLOGICAL SYSTEM

- Motor Seizure Disorders
- Brain Tumors
- Motor Dysfunction due to Neurological Disorder
- Cerebral Palsy
- Meningomyelocele
- Communication Impairment Associated with Neurological Disorder

MENTAL and EMOTIONAL DISORDERS

- Mental Retardation
- Organic Mental Disorders
- Schizophrenic, Delusional, Schizoaffective And Other Psychotic Disorders
- Mood Disorders
- Anxiety Disorders
- Somatoform, Eating and Tic Disorders
- Personality Disorders
- Psychoactive Substance Dependence Disorders
- Autistic Disorder and Other Pervasive Developmental Disorders
- Attention Deficit Hyperactivity Disorder
- Developmental and Emotional Disorders of Newborn and Younger Infants

IMMUNE SYSTEM

- Human Immunodeficiency Virus (HIV) Infection
- Systemic Lupus Erythematosus
- Systemic Vasculitis
- Systemic Sclerosis and Scleroderma
- Polymyositis or Dermatomyositis
- Undifferentiated Connective Tissue Disorder
- Congenital Immune Deficiency Disease

ASSESSMENT OF FUNCTIONAL IMPAIRMENTS

In recent years, several major changes have been made in the definition and guidelines for determination of a child's disability and his or her eligibility for SSI.

THE ZEBLEY DECISION

On February 20, 1990, the U. S. Supreme Court decided a class-action lawsuit, *Sullivan v. Zebley*.

The court held that SSA's disability determination process for children violated the Social Security Act because the listings did not provide an assessment of the child's overall functional impairment. They ruled that the agency must use an evaluation process for children comparable to the one it uses for adults. As a result, SSA completely revised its rules for evaluating children's disabilities, publishing new regulations in February 1991.

The new rules added a functional requirement to determine whether a child's impairments so restrict his or her ability to engage in age-appropriate behaviors or activities.

The *Zebley* decision expanded eligibility for thousands of children who apply for SSI disability benefits and allowed previously denied claims to be re-evaluated.

The welfare law of 1996 changed this process, but retained the functional evaluation in a varied form.

THE NEW CHILDREN'S SSI RULES

The 1996 welfare law made the rules for eligibility more stringent.

- A child's condition has to be more severe to meet the new definition of disability.
- Children's functional limitations – what a child cannot do – must be “marked and severe”.
- Behavior problems caused by mental or emotional conditions are also considered differently.
- Except in emergencies, children who get large back-benefit payments can use the money only for expenses related to their condition, such as medical treatment, education or job-skills training, special equipment, housing modifications and other items that Social Security considers appropriate.
- Redetermination of previously eligible children is done using the new childhood disability standard.

Because of these changes, Social Security needs to know not only a child's impairment, but how his or her condition affects his/her ability to function in various areas according to age.

Useful Information For Social Security About Your Child's Functioning

Social Security workers need to know how your child's condition affects his or her ability to function in these areas according to his or her age:

Acquiring and Using Information

- Can the child learn, understand and solve problems?
- Remember information?
- Describe events?
- Respond to directions or questions?
- Ask questions to get information?
- Express feelings and ideas?
- Is the child's speech intelligible?
- Is the child's hearing adequate for conversation?

A child who can't perform some of these activities may have impaired functioning.

Attending and Completing Tasks

- Can the child keep focused on an activity or task?
- Perform the activity or complete the task in the amount of time reasonably expected for his or her age?

A child who is unable to play, do household chores or study may have impaired functioning.

Interacting and Relating with Others

- Can the child establish relationships with parents, other adults and peers?
- Does the child interact appropriately?
- Does the child get along with family members, friends, classmates and teachers?
- Does the child have a history of running away, showing physical aggression towards others or avoiding interpersonal relationships?

A child who doesn't interact socially in appropriate ways may have impaired functioning.

Caring for Self

- Can the child do self-care activities such as eating, toileting, bathing and dressing?
- Maintain personal hygiene?
- Follow prescribed medication or therapy schedule?
- Use safety precautions?

A child who fails to develop or use self-care skills or who has a pattern of injuring himself or herself may have impaired functioning.

Moving About and Manipulating Objects

- Does the child have the fine and gross motor skills necessary for play, sports and everyday physical activities other than self-care?

A child who can't perform some of these activities may have impaired functioning.

Health and Physical Well-Being

- Does the child have other health or physical difficulties beyond moving about and manipulating objects which should be noted in the assessment?

A child may have additional difficulties in functioning not covered under the above categories.

COLLECTING DOCUMENTATION OF DISABILITY

Many disability claims fail because the Disability Determination Service (DDS) doesn't have adequate information about the child's impairment and functioning. It is important for the DDS to have both a complete medical history and a functional assessment documenting what the child CANNOT do.

Remember, the DDS disability examiner will not see the child. Reports describing what the child can and cannot do are often the only information the DDS examiner will have about how the child functions day-to-day.

Remember to keep a copy of everything you submit. A family does not have to have ALL the information before applying. The evaluation takes some time and documents can be added later – though it's important to supply them as soon as possible.

SUGGESTIONS TO HELP GET THAT INFORMATION TOGETHER:

- **Make a list of people social security should contact.**

The list should have names, addresses and telephone numbers of all hospitals, doctors and other health professionals who have treated the child (with dates of treatment), and of teachers, relatives and friends who know how the child functions. Parents and advocates should keep a copy of this list because it will be useful later.

Useful sources of information and documentation include:

- Doctors, psychologists, nurses, clinics, hospitals;
- Developmental center, day care and preschool workers; school counselors and teachers;
- Therapists and aides (such as physical, occupational, speech);
- Social workers and social welfare agencies;
- Mental health counselors;
- Early intervention specialists; clergy, relatives, friends and parents.

- **Make notes about all the child's limitations and medical problems,** past and present, even if they do not seem related or severe enough to be considered disabling. These notes should describe all the child's physical, mental, emotional, learning and behavioral impairments. Examples are very helpful to the DDS.

- **Get narrative reports and specific examples.**
If possible, ask sources to submit narrative reports in addition to their formal records. These reports should describe in detail how the disability interferes with the child's age-appropriate development and activities. Specific examples of functional limitations are extremely useful.

- **Collect medical and mental health records.**
Parents should get copies of records documenting all medical problems, past or present, including the dosage and frequency of any medication the child takes.

- **Collect school records and written reports or letters from other people who see your child regularly.**
Because SSA no longer relies only on medical evidence of a child's disability, it is also important to submit all relevant records from non-medical treating sources. Evidence that indicates whether the child cannot do things that other children around the same age do ("age appropriate" behaviors and activities) is a critical part of the disability decision.

- **Submit as much of this evidence as possible with the initial application.**
The SSA field office will forward this information to the disability examiner. But even if some of the information is still missing, apply anyway and send in the rest as it becomes available.

DISABILITY REVIEWS AND REDETERMINATIONS

CONTINUING DISABILITY REVIEW:

- Children’s cases must be reviewed every three years, unless the condition is unlikely to improve, to decide if the child still qualifies for benefits. At this case review, parents have to show that their child is receiving treatment that is “medically necessary” and “available.”
- Children who qualified because of low birth weight will have their cases reviewed soon after their first birthday.
- All children must have their cases reviewed when they turn 18 years old, using the adult eligibility rules.

REDETERMINATIONS

SSA periodically reviews family income, resources, and living arrangements to be sure a child is still eligible for SSI and is getting the right amount of SSI payments.

HOW DOES SSA DO A REDETERMINATION?

There are three ways that SSA does a redetermination:

- by telephone interview; or
- in person; or
- by mail.

For telephone and in person interviews, SSA sends a letter asking you to telephone or come into your local SSA office for a redetermination. The letter tells you what time to call or come to the office. SSA staff will fill out the forms during the interview based on information you give to them.

If you are not able to make the scheduled appointment, call SSA; they will make a new appointment that is more convenient.

For a redetermination conducted by mail, SSA sends you a short redetermination form for you to complete and return. If you have a representative payee, he or she must complete the form for you.

If you need help completing a redetermination form you receive in the mail, call SSA or visit your local SSA office. SSA staff will help you fill it out.

THE APPEALS PROCESS

WHY APPEAL THE DENIAL OF AN SSI APPLICATION?

SSA turns down well over a third of applications for children's SSI benefits. However, when applicants appeal these decisions, many are able to reverse the denial. Then they may receive retroactive benefits, back to the date of the original application.

HOW AND WHEN DOES THE APPEALS PROCESS BEGIN?

If an applicant is found ineligible, Social Security sends a "notice of denial," which explains whether the denial is based on financial or medical reasons. The applicant has 60 days from the date the letter is received (which Social Security estimates to be five days after the date on the denial letter) to file an appeal.

WHAT IS THE APPEALS PROCESS?

There are four steps or stages in the appeals process. An applicant may be successful at any of these stages, but must follow each step in the designated order:

1. Reconsideration – depending on the reason for the denial, an informal conference (denial on financial grounds) or review by the DDS (for denial as not disabled).
2. Administrative Law Judge (ALJ) hearing – review by an independent SSA employee trained to judge disability cases. At the formal hearing, witnesses are heard, additional evidence presented and the child is seen for the first time by a decision-maker.
3. Social Security Appeals Council review – the final level of review in the administrative process. The Appeals Council can grant or deny a request for review or review an ALJ decision on its "own motion". It will accept new evidence but does not hear witnesses or see the child.
4. Civil lawsuit in United States District Court

An applicant has 60 days to complete each step. At each stage, this time begins to run on the date the applicant receives the adverse decision.

IS LEGAL ASSISTANCE NECESSARY?

Yes. Though it's not required, legal assistance is extremely helpful for an appeal, especially after reconsideration. Once the child receives a "notice of denial", we strongly advise parents to ask for reconsideration. If benefits are again denied (as they often are) the appeals process can become complicated. Parents should IMMEDIATELY seek legal assistance. The local Vermont Legal Aid Office (*see page 30*) may be able to help if parents can't afford an attorney; their lawyers and paralegals handle many such hearings.

PLAN FOR ACHIEVING SELF-SUPPORT

The SSI law permits a person with a disability to set aside income and/or resources for a specified period for a work goal – education, vocational training, or starting a business. This is called a **Plan for Achieving Self-Support (PASS)**.

SSA doesn't count income and resources used for the PASS in determining SSI financial eligibility. An approved PASS can thus help a child become eligible for SSI, keep SSI benefits or receive a higher SSI payment. **A child must be at least 15 before SSA will approve a PASS.**

PASS REQUIREMENTS

The PASS must:

- Be designed specifically for the child applying for or receiving SSI;
- Be in writing;
- Have a specific work goal the child is capable of performing;
- Have a specific time frame for reaching the goal. The PASS should state when the plan starts and how long it will take to achieve the goals. If the PASS is to pay for college or a vocational training program, the goal would normally be achieved when the degree or certificate is received by the child/young adult;
- Show what money and other resources received will be used to reach the goal;
- List the items and/or activities the money will be spent on and how those relate to the child's vocational goals;
- Show how the money set aside will be kept identifiable from other funds; and
- Be approved by SSA.

ITEMS THAT CAN BE FUNDED WITH A PASS

Here are some examples of what can be paid for with a PASS:

- Tuition at a trade school or college
- Support for living expenses, away from home, while receiving job training
- Tools and equipment used on a job
- Supplies to start a business

- Prosthetic devices, including hearing and vision aids
- Adaptive devices at home, work or in a vehicle to make the work place accessible
- A vehicle that is essential for work or school
- Job-coach services and other costs associated with supported employment

TIME LIMITS FOR THE PASS

Initially a PASS can be approved by SSA for only up to 18 months. If not completed, it can then be extended for 18 more months, and then an additional 12 months, if needed, totaling 48 months. If the child needs more time at the end of 48 months, six month extensions can be granted on a case-by-case basis.

APPEALS

If the SSA denies a PASS proposal, the child has a right to appeal. The first appeal is considered a request for reconsideration and the process is the same as appealing a denial of an application for SSI.