NASET's Educating Children with Severe Disabilities Series

Financial and Health Insurance Issues

Here you will find expert suggestions on dealing with all financial and health issues surrounding individuals with disabilities. Here you will find information on Medicare, Medicaid, Social Security Insurance, Social Security Disability Insurance, Food Stamps etc.

Introduction

To properly plan for the financial future of a student with disabilities, students and parents must be aware of the options and incentives that are available during the transition process. A very important part of this process is helping children with disabilities manage to the best of their ability their finances or other affairs. The purpose of this section is to give you, the special educator, and a strong working knowledge of the financial considerations that all children with disabilities must face in their transition to adult life.

This section will also focus on health insurance issues facing parents and individuals with disabilities. Chronic illness, disability, or severe injury creates great stress for family and friends. The adjustment for a family with a child who has a severe or complex health issue can be very intense and taxing; the special needs of this child require a focus on many issues. Concerns surrounding the child's well-being, health, daily life, and constantly changing future expectations are magnified. As the health field changes and technology and terminology expand, parents must learn new skills and acquire a wide range of knowledge to ensure that a child's ongoing health needs are properly addressed.

With the expansion of technology and improved medical care also comes the burden of growing medical costs. As a result, parents of children with chronic disabilities have the added anxiety of finding the resources necessary for medical attention and recommended equipment.

Many people with disabilities are eligible for benefits under one or more of several government programs. These programs are designed to protect the person with a disability by making sure that the person's financial resources are sufficient to provide the basic necessities of life--food, clothing, and health care.

To plan for the future of a child with disabilities, individuals must be aware of and use the many programs sponsored by the federal government and operated through a federal state partnership. These are called entitlement programs. Some of them are provided for large portions of the population in general--not just for persons with disabilities; other programs are specifically for people with disabilities. With a well-planned combination of services and, where possible, by supplementing these services with private assets, a parent can establish a relatively secure financial future for a son or daughter.

Benefits include more than money: The individual may also be eligible for valuable services such as health care, vocational rehabilitation, supported employment, subsidized housing and personal attendant care. Assets acquired through inheritance may affect eligibility for those benefits. Therefore, in order to protect the individual’s eligibility for government benefits at some point in the future and to provide for his or her long-term needs, the parent may want to consider establishing an individual estate plan.

The need for a clear-cut, long-range plan is needed in cases where a daughter/son has cognitive or mental disabilities. Mental illness and cognitive disabilities often impair a person's ability to manage his or her own finances. Parents, will therefore have to provide for the present as well as the future of their daughter/son.

The purpose of this section is to give you a strong working knowledge of health insurance issues for individuals with disabilities. After reading this section, you should understand the following:

Insurance options
HMOs (health management organizations)
PPOs (preferred provider organizations)
Indemnity plans
Medicare
Medicaid
Medicaid waivers
Social Security Administration
Supplemental Security Income (SSI)
Criteria for determining SSI
How to sign up for SSI benefits
What to bring when signing up for SSI benefits
Work incentives
Social Security Disability Insurance (SSDI)
Food stamps
Entitlement Programs
Exploring Insurance Options
Kinds of Insurance Policies
Medicare
Medicaid
Medicaid Waivers

Financial Planning

Planning will entail taking inventory of a family's financial assets. Most families are surprised to learn that they do have a variety of resources within their reach. Some of them may include:

- standard government benefits;
- savings;
- family assistance;
- parents' estate;
- inheritances;
- property;
- investments;
- military benefits;
- insurance;
- house or home;
- resources from other family members and friends.

While a family's financial situation is confidential, when it comes to parents' financing their children's future there are several paths that one can explore depending on the nature and severity of the child's disability and the personal assets of the family.

Your role in this area is not to be a financial advisor, but to inform and assist students and their parents in fully understanding their options and rights. The following options should be explored and any one or a combination may be sufficient for a particular situation:

- using the family's own financial assets
- government assistance through a variety of programs

Since support from a parent's personal assets is self-explanatory, we will focus on the government programs that can provide financial support for individuals with disabilities.

Social Security Administration

The Social Security Administration (SSA) directs two programs that can be of financial benefit to eligible individuals with disabilities throughout the transition process. These programs are:

- Supplemental Security Income (SSI) program
- Social Security Disability Insurance (SSDI) program

Because the Social Security Administration considers many variables before determining if a person is eligible for SSI or SSDI benefits, the discussion here is intended only as an overview to the benefits of these programs. Ultimately, an individual's eligibility can be determined only by contacting the Social Security Administration and filing an application. Your awareness of these entitlement programs will assist parents in this very crucial aspect of the transition process.

Supplemental Security Income (SSI)

The SSI program is targeted for individuals who are both (a) in financial need, and (b) blind or disabled. People who get SSI usually receive food stamps and Medicaid, too. The evaluation process to determine eligibility varies, depending upon whether the applicant is under the age of 18 or over. Recently, there have been many significant changes in how the SSA determines the SSI eligibility of individuals under the age of 18. These changes are expected to make it easier for children and youth with disabilities to qualify for SSI benefits. More information about these changes and the specific evaluation process the SSA now uses for individuals under the age of 18 is available by contacting the Social Security Administration directly. When a child reaches the age of 18, the Social Security Administration no longer considers the income and resources of parents in determining if the youth is eligible for benefits.

Under the SSI program, individuals over the age of 18 are eligible to receive monthly payments if they:

have little or no income or resources such as savings accounts
are considered medically disabled or blind

do not work or earn less than a certain amount, defined by the Social Security Administration as substantial gainful activity (SGA).

Criteria for Determining SSI Benefits

To determine a person's financial need, the Social Security Administration considers the following:

The person's place of residence: SSI payments may be reduced by different percentages, depending on the individual's residence. People who live in city or county rest homes, halfway houses, or other public institutions usually cannot get SSI checks, but there are some exceptions. A person living in a public operated community residence that serves no more than sixteen people may get SSI. Anyone living in a public institution mainly to attend approved educational or job training that will help him or her get a job may get SSI. Those living in a public emergency shelter for the homeless may be able to get SSI checks. If an individual lives in a public or private institution and Medicaid is paying more than half the cost of the care, he or she may get a small SSI check.

The parent's employment status: An individual's SSI payments may be determined by parental income and employment status. This issue should be explored fully so that an individual with disability can receive the proper assistance.

Income and things owned by an individual with a disability: Whether an individual can get SSI also depends on what he or she owns and how much income is coming in, such as wages, Social Security checks, and pensions. Income also includes such non cash items received as food, clothing, or shelter. If a person is married, the SSA will also look at the income of the spouse and the things the spouse owns. For someone under 18, SSA may look at the income of the parents and the things they own. For a sponsored alien, they may also look at the income of the sponsor and what he or she owns.

For specific information and criteria for any of the above factors have the parents contact their local Social Security Administration office.

Before an individual with a disability can get SSI, he or she must also meet other rules. These rules are:

- One must live in the United States or Northern Mariana Islands.
- One must be a U.S. citizen or be in the United States legally.
- If an individual is eligible for Social Security or other benefits, then he or she must apply for them. (Eligible persons can get both SSI and Social Security checks if eligible for both.) If disabled, one must accept vocational rehabilitation services if they're offered.

How to Sign Up for SSI Benefits

It's easy. Just have the student and his or her parents visit the local Social Security office or call (800)772-1213 for an appointment with a Social Security representative who will help them sign up. SSI should be applied for right away; this benefit cannot start before the day one applies. Parents or guardians can apply for children under the age of 18 who are blind or disabled.

What to Bring When Signing Up for SSI Benefits

Help your students and their parents understand that the following things are required before applying for SSI benefits. Even if applicants don't have all of the things listed, however, suggest they sign up anyway. The people in the Social Security office are there to help applicants get whatever is needed.

- Social Security card or a record of Social Security number
- Birth certificate or other proof of age
- Information about residence, for example, a home with a mortgage or a lease and landlord's name
- Payroll slips, bank books, insurance policies, car registration, burial fund records, and other information about income and the things that are owned
- Medical information supporting the disability. When signing up for disability, the names, addresses, and telephone numbers of doctors, hospitals, and clinics are required. SSI checks can go directly into an individual's bank, so have the family bring a checkbook or any other papers that show names and account numbers. Many people choose to have their checks sent to the bank because they find it safer and easier than getting their checks by mail.
- Work Incentives

The Social Security Administration offers two programs that can be of benefit to individuals with disabilities. The SSI and SSDI programs offer financial and medical benefits to eligible persons with disabilities. In addition, both programs have work incentives that make it possible for individuals with disabilities to work without an immediate loss of benefits. Here is how they work.

SSI Program Work Incentives

SSI work incentives are exactly that -- additional incentives that allow students with disabilities to increase their income while maintaining needed SSI cash assistance benefits. SSI work incentives allow students to participate in paid work situations and maintain their SSI benefits while they are in school. As a planning tool, work incentives provide students, parents, school personnel, and other IEP/transition team members with potential resources for additional post-secondary training and other forms of support when a student exits school. SSI program work incentives protect SSI benefits for students while they participate in paid employment.

Accessing SSI work incentives during the transition process expands current and future opportunities for many students with disabilities. Students with disabilities can:

- Engage in paid employment.
- Increase their income without decreasing their SSI benefits or eligibility for other benefits such as Medicaid (in most states).
- Offset expenses incurred as a result of their work.

Save for further post-secondary education and training or to start their own business.

According to the The National Transition Network (1998), transition planning process must include establishing the student's eligibility for SSI benefits and providing the student with real work experience during the transition period -- ages 14 (or younger, if appropriate) - 21. For a student with a disability to benefit from SSI work incentives, the student must be (1) receiving or eligible for SSI cash assistance benefits, and (2) engaged in work experiences as part of their transition program.

SSI work incentives available to transition-age students include: Earned Income Exclusion, Student Earned Income Exclusion (SEIE), and Impairment-Related Work expenses (IRWE), Plan for Achieving Self-Support (PASS), Blind Work Expense (BWE), and Property Essential to Self-Support (PESS). Each of the SSI work incentives is an income or resource exclusion that combines to assist individuals with disabilities in maintaining necessary SSI benefits until they are self-sufficient. These incentives can be particularly helpful in designing community-based, paid employment transition programs for students without decreasing the cash assistance benefits provided by the SSI program.

There are a number of work incentives under the SSI program. These include:
A-Section 1619a: Provisions under Section 1619a of the Employment Opportunities for Disabled Americans Act allow people to continue to receive special SSI monthly cash payments after their earned income is at the amount designated as the Substantial Gainful Activity (SGA) level (currently $500 a month). The Social Security Administration uses a formula to determine the amount of SSI benefits an individual with a disability will continue to receive. In most cases, people remain eligible for Medicaid and state-funded attendant care benefits (U.S. Department of Health and Human Services, 1990, October).
B-Section 1619b: Provisions under Section 1619b of the Employment Opportunities for Disabled Americans Act allow most individuals to keep Medicaid benefits after they stop receiving monthly SSI checks. The law requires that a person's medical condition be reviewed within 12 months of entering the 1619b status to ensure the person still has a disability. A person must apply for these benefits before his or her regular SSI benefits actually stop.
C-Impairment-related work expenses (IRWE). IRWEs are the costs for services or materials a person needs to be able to work. Social Security deducts these costs from an individual's SGA when calculating how much money that person should receive in his or her monthly check. Services and materials can be deducted as IRWEs only if the person pays for the costs himself and receives no reimbursement for them. The services or materials must be necessary because of a person's disability. They can not be costs that a person without a disability would have if she or he were to hold the same type of job. According to the U.S. Department of Health and Human Services (1990, August), examples of IRWEs are the cost of wheelchairs, pacemakers, respirators, braces, and artificial limbs. Work-related equipment such as one-handed typewriters, electronic visual aids, and Braille devices may also be deductible. Other costs such as attendant care needed to prepare for and go to or from work are often deductible as well. The cost of a job coach for a person has just recently been allowed as an IRWE.

D-Plan for Achieving Self Support (PASS: PASS is a work incentive program that enables a person with a disability to receive earned and unearned income and to set some or all of these funds aside for up to 48 months. The purpose of the program is to help individuals accumulate resources in order to pursue a specific work goal, such as "education, vocational training, or starting a business, or purchase of work-related equipment" (U.S. Department of Health and Human Services, 1990, October, p. 3). Thus, the PASS program is a means of encouraging and empowering individuals to become financially self-supporting.

A PASS program must be in writing and must include a realistic work goal, a date for achieving the goal, a clear savings/spending plan, and a method for keeping track of the funds that are set aside. Social Security must approve an individual's PASS program. It is helpful to initiate a PASS prior to receiving transitional and/or supported employment services, but a PASS program can also be established after a person goes to work. The income and resources set aside under a plan are excluded from the SSI income and resource tests. SSI payments themselves cannot be set aside in a PASS, and individuals must have some type of resources or income other than the SSI check to establish a PASS.

SSDI Program Work Incentives

The SSDI program also has work incentives. As with SSI work incentives, impairment-related work expenses can be deducted from the earnings on which Substantial Gainful Activity (SGA) is calculated. Other work incentives include a trial work period, extended period of eligibility, and extended Medicare coverage.

The trial work period allows individuals with disabilities to test their ability to work, without fear of losing SSDI benefits. The trial period is for nine months of work, which need not be consecutive. During or after this time, if an individual demonstrates the ability to earn above the SGA limit of $500 a month, despite his or her disability, he or she may no longer be considered disabled by the Social Security Administration. Benefits would be discontinued three months later (considered a grace period).

The extended period of eligibility is an additional work incentive tied to the nine-month trial period. This incentive exists to ensure that the individual with a disability has sufficient time to develop the financial and occupational stability necessary in order to maintain independence. Basically, individuals can be reinstated to SSDI benefits if their earnings fall below the SGA level at any time during the extended period (36 months). Furthermore, individuals do not need to file a new application or have a new disability determination. Benefits are reinstated without a waiting period.

Most people with disabilities would rather work than try to live on disability benefits. There are a number of special rules for providing cash benefits and Medicare while they attempt to work. These rules are called work incentives. Be familiar with these disability work incentives so they can be used to the individual's advantage.

If an individual is receiving Social Security disability benefits, the following work incentives apply:
A-Trial Work Period: For nine months (not necessarily consecutive), people may earn as much as they can without affecting their benefits. (The nine months of work must fall within a five-year period before the trial work period can end.) A trial work month is any month in which they earn more than $200. After the trial work period ends, the work is evaluated to see if it is "substantial." If earnings do not average more than $500 a month, benefits will generally continue. If earnings do average more than $500 a month, benefits will continue for a three-month grace period before they stop.
B-Extended Period of Eligibility: For thirty-six months after a successful trial work period, an individual who is still disabled will be eligible to receive a monthly benefit without a new application for any month earnings drop below $500.
C-Deductions for Impairment-Related Expenses: Work expenses related to the disability will be discounted in figuring whether earnings constitute substantial work.
D-Medicare Continuation: Medicare coverage will continue for thirty-nine months beyond the trial work period. If Medicare coverage stops because of work, monthly premiums may be purchased.

Different rules apply to SSI recipients who work. For more information about Social Security and SSI work incentives, you may want to ask for a copy of the booklet, Working While Disabled-How Social Security Can Help (Publication No. 05-10095).

Social Security Disability Insurance (SSDI)

The SSDI program is a bit different, because it considers the employment status of the applicant's parents. "SSDI benefits are paid to persons who become disabled before the age of 22 if at least one of their parents had worked a certain amount of time under Social Security but is now disabled, retired, and/or deceased" (National Association of State Directors of Special Education 1990, p. 9). As with SSI, eligibility for SSDI generally makes an individual eligible for food stamps and Medicaid benefits as well.

Be aware that changes in legislation might result in a reduction of benefits. Recent legislation, however, has made major changes in both the SSI and SSDI programs to encourage people receiving these benefits to try to work and become independent. These changes are called work incentives, because they make it possible for individuals with disabilities to work without an immediate loss of benefits.

Whatever financial status a family has at the time a child turns 18, assist your students and their families by providing a thorough knowledge of the student's financial entitlements.

Plan for Achieving Self-support (PASS)

The Plan for Achieving Self-support (PASS) is a work incentive that allows an individual to set aside income and/or resources for a specified period of time to achieve a work goal For example, an individual may set aside money for postsecondary education, the purchase of job-coaching support, personal transportation, job-related equipment, or to start a business. The income and/or resources set aside in a PASS do not count in determining SSI benefits. Nor may SSI cash benefits be used to support a PASS. When appropriate, a PASS may be used in conjunction with other SSI work incentives. If a student under age 18 cannot satisfy the SSI income eligibility requirement only because his or her parent's income is too high, the student may apply for a PASS incentive through which their parents can set aside enough income to make the student eligible for SSI benefits.

The PASS is similar to the IEP/Transition Plan: It establishes job-related goals and objectives. Because of these similarities, it is possible to incorporate a PASS into the IEP/transition plan. A transition student may benefit from a PASS while in school or upon exiting. The basic requirements for a PASS include:

- A feasible and reasonable occupational goal
- A defined timetable.
- The need for income or resources, other than SSI benefits, to be set aside.
- An explanation of expenditures to be covered by the set-aside funds.
- A student wishing to incorporate a PASS into his/her transition program should:
- Request assistance if needed from professionals, counselors, or other IEP/transition team members
- Obtain the eight page PASS application (Appendix E), instruction sheet, and SSA publication Red Book On Work Incentives in your school counseling office, special education office, or from the local SSA Office
- Gather all income and resource information that will be required.
- Identify the job goal and steps for achieving it (which may be incorporated into the IEP/transition plan.
- Work with his/her Vocational Rehabilitation Counselor to develop the plan.
- Make and keep an appointment with the local SSA office.
- Complete the PASS application and submit it to local SSA office.
- Answer questions from the SSI-PASS Cadre about the application.

The PASS should be considered during the IEP/transition development process even if it is not to be used while the individual is still a student. A PASS may be used by any individual participating in SSI at any age. Some students can benefit from a PASS while they are in school, and also after they leave school to further their vocational goal by purchasing additional training or transportation, for example. As part of the transition planning process, the planning team may incorporate the future use of a PASS into the student's IEP/transition plan.

The most likely candidate for a PASS incentive are students who currently are receiving SSI benefits, want to work and have work goals in their IEP, are in school or a training program or plan to complete postsecondary training, or plan to start their own business.

A PASS incentive can be used to support a number of expenses related to employment goals, including:

- Tuition, fees, books, and supplies for school or training programs.
- Supported employment services, including a job coach.
- Attendant care.
- Equipment and tools needed to work.
- Transportation.

A PASS incentive must:

- Be specifically designed for the individual with a disability.
- Be in writing
- Have a specific career goal which the individual is capable of achieving.
- Have a specific time frame for reaching the goal.
- Show what money or other resources the individual will use to reach the goal.
- Show how the money and resources will be used.
- Show how the money set aside in the PASS will be kept separate from other funds, i.e., a separate bank account.
- Be approved by the SSA.
- Be reviewed periodically to assure compliance.

Income and resources that are set aside in a PASS are excluded under the SSI income and resources tests. Any transition student who receives SSI benefits or could qualify for them, can have a PASS. A student, for example, whose income exceeds SSI requirements, may develop a PASS to maintain his or her SSI eligibility while pursuing work goals.

To receive a PASS an individual must complete a PASS application and submit it to the SSA office. Each PASS is reviewed for approval by the local PASS cadre. This process can take up to three months to complete. Anyone may help a student develop a PASS, including special education professionals and other school personnel, vocational counselors, social workers, employers, and private PASS vendors. A distinct advantage of a PASS is that it allows the student to be proactive in securing necessary training, support, or services to enhance employment opportunities.

Blind Work Expenses (BWE)

SSA has special rules for people who are blind, including allowing them to earn a higher income (Substantial Gainful Activity [SGA]) and maintain SSI eligibility. Blindness is defined as central visual acuity of 20/200 or less in the better eye with best correction which has lasted or is expected to last a year or longer. Blind Work Expenses (BWE) is a work incentive that allows a blind person to deduct certain expenses needed to earn an income from their earned income when determining SSI eligibility and payment amount. For individuals who are blind, the BWE work incentive is more advantageous than the IRWE. Examples of BWE include: guide dog expenses; transportation; federal, state, and local income taxes; social security taxes; attendant care services; visual and sensory aids; translation of materials into Braille; professional association fees; and union dues. When developing transition plans for students who are blind, school personnel and parents should contact their regional SSA office to get more specific information on SSA programs and benefits available.

Property Essential to Self-Support (PESS)

PESS allows a person to exclude certain resources which are essential to employment for self-support. For example, property which is used in a trade or business or required by a person as an employee is totally excluded when determining resources for SSI eligibility or payment determination. While the PESS may have little application for secondary transition students, it may have utility for some students when they enter the work force. A student, for example, who is trained in carpentry may be required to supply his or her own tools as terms of employment. Under a PESS the value of these tools would not be counted as a resource,

The Role of School Personnel in Accessing SSI Work Incentives

School personnel responsible for the successful transition of students from school to work and independent living can perform several functions to support the use of SSI work incentives as a viable part of transition planning. Specifically school personnel can:

- Identify students who are currently receiving SSI benefits and students who may be or will eligible.
- Incorporate SSI work incentives into the IEP/transition planning process and community-based employment.
- Inform students and parents about SSI program benefits and eligibility and work incentives when transition planning begins (age 14, or younger, if appropriate).
- Assist students and parents in collecting appropriate documentation on student's disability, limitations, performance, and behaviors that will assist SSA in determination or redetermination of eligibility.
- Establish a close relationship with local SSA staff to facilitate communication among students, parents, school personnel, and SSA staff.
- Collaborate with and engage other professionals (i.e., vocational rehabilitation, SSA, and human services) who share a common interest in students' secondary and postsecondary success.

Identification of Potentially Eligible Students

Students eligible to receive SSI benefits can be identified through medical and psychological data alone. Some disabilities (e.g. blindness, hearing impairments, significant speech impairments, mental retardation and autism as measured by an IQ under 60, and Cerebral Palsy with severe motor involvement) can be assumed to meet SSA's medically-based criteria. Students who exhibit cognitive and emotional problems that will interfere with their ability to work may also be eligible. Students who are not receiving SSI benefits who may be, or will become, eligible at age 18 should be identified during the initial transition planning process. School personnel can also identify students who are receiving or will be eligible to receive SSDI benefits.

Incorporate SSI Work Incentives Into the IEP/Transition Planning Process

Incorporating SSI work incentives into a student's IEP/transition plan can provide excellent opportunities for students, parents, and other IEP/transition team members to explore employment opportunities while the student is still in school. These incentives can also benefit students after they are out of school. To be eligible for SSI work incentives, a student must first be receiving SSI benefits and be engaged in paid work

experiences (CBVE) as part of their transition plan. Therefore, it is important to explore and include work incentives in a student's transition plan in the very early stages of the process. This will assist students, parents, and other IEP/transition plan members in identifying specific steps that will be required to allow students to establish postschool goals and objectives and participate in school-sponsored employment opportunities. SSI work incentives can also help students plan for and save money toward a future career goal. Participating in SSI work incentives will, in most cases, allow students to increase their monthly income while still retaining their SSI benefits, including Medicaid.

Inform Students and Parent of SSI Program Benefits and Eligibility and Work Incentives

School personnel can introduce and explain SSI work incentives to students and parents during the early stages of transition planning. Successful transition planning requires that school personnel, parents, students, and adult service providers work together to design a sequence of activities that will lead toward community participation and employment when a student exits school. Typically, community-based vocational education will be a focus of the initial transition discussions. Introducing work incentives early in the transition process establishes paid employment as a viable transition goal and allows students, parents, and other IEP/transition team members to broaden their collective thinking regarding available resources and the potential benefits of SSI work incentives. Just as school personnel inform parents and students about vocational rehabilitation and other adult services, so should they inform parents and help them gain knowledge about the SSI program eligibility requirements, benefits, and work incentives. As part of the transition planning process, school personnel routinely collect information on students and their families to assist in the design of plans that meet the goals and circumstances of the students and their family. Information regarding SSI eligibility or potential eligibility should be included in this information.

Assist Students and Parents in Applying and Reapplying for SSI Benefits

Many students and parents are unfamiliar with the SSI program and its application. School personnel can assist students and parents in the SSI application process by helping them complete the application form and referring them to the appropriate local SSA representatives. Once the student is determined eligible for benefits, the greater the opportunities for incorporating work incentives into the transition plan. It takes an average of three months to complete the application process, thus, it is crucial to begin the process during the early stages of the student's transition planning.

It is very important that all relevant documents—including medical history, school history, and functional limitations associated with any transition program work experiences—are gathered and organized for submission to the local SSA office. School staff can help gather appropriate school, social, and medical records, both past and present; make a list of all persons SSA may need to contact; and prepare school-based reports on the functional limitations of the student observed in school and in community-based settings. These reports may be excerpted from current assessment reports and/or IEPs/transition plans.

Short written reports with formal records that include specific examples of the student's functional limitations are extremely important. Information from clergy, relatives, family, and friends also can be useful when they describe specific examples of the student's functional limitations (Bazelon, 1997).

School personnel can also help parents develop their own anecdotal information on their son's/daughter's performance at home. Staff can assist students and parents in obtaining short, written reports from other people who have close contact or work with the student. These may include employers, job-site supervisors, or coworkers of students in community work settings. It's helpful when school staff and parents keep a diary of activities and functional limitations of students they observe over time.

Students and parents should ask all doctors who have seen the student for hospital, medical and prescription records including reasons for medications. Hospital records should include dates, names of hospitals and attending doctors, and reasons for hospitalization. Sources for such documentation include:

- Doctors, psychologists, nurses, clinics, and hospitals.
- Developmental centers, day care and pre school, school counselors and professionals.
- Therapists.
- Mental health counselors.
- Social workers and welfare agencies.

One of the most significant roles school personnel can play is providing SSA with information that documents observed student limitations in a variety of settings including school and community training and employment sites. Special education professionals, related service personnel, job coaches, and other school staff are in an excellent position to provide this information because they work with the student on a regular basis. Documented observations of the student's functional limitations by school personnel that impact or will impact on work performance will assist SSA examiners in the determination process.

School personnel can also assist students and parents with the redetermination process of SSI eligibility, which is required once the student reaches age 18. School personnel can help students and parents understand the differences in eligibility criteria for adults (18 and over) and children (under 18 years of age), and should be prepared to address questions regarding potential benefit loss, including Medicaid, if appropriate. Knowing and understanding the eligibility criteria allows school personnel and students and parents to develop appropriate documentation and records for the redetermination process. Often school assessment reports and IEPs/transition plans contain pertinent information regarding the student's functional limitations across environments; this is a critical component for initial determination and redetermination of eligibility.

Establish a Cooperative Working Relationship with the Local SSA Staff and the Regional PASS Cadre

It has been pointed out in this handbook that SSA staff have in-depth knowledge and experience in assisting youth with disabilities and parents in applying for SSI benefits and work incentives. Many local SSA offices have specific staff (e.g., Work Incentives Liaisons and PASS Specialists) assigned to work with transitioning youth and the SSI program. It is important for school personnel and other IEP/transition team members to establish a rapport with these individuals. This will assist school personnel, the student and his/her parents, and other IEP/transition team members in facilitating the application process.

Regional PASS cadres have been established and operate throughout the country to specifically assist school personnel and the IEP/transition team in writing, reviewing, and evaluating PASSes. These cadres can be very helpful in developing a successful PASS application.

Collaborate With and Engage Other Professionals in Applying for SSI Benefits and Work Incentives

Just as all members of the IEP team and others involved in the transition of youth with disabilities must support the goals and objectives of the students' IEP/transition plan, so is it important that they be familiar with and support the SSI application and work incentives processes for the student, especially when it is a component of the student's plan. Both application processes require submitting detailed documentation about the student to the SSA office. Various members of the student's IEP/transition team may have different knowledge about the student. For example, a student's family and friends will interact with the student in different environments than school personnel and will be familiar with different aspects of the student's behavior (e.g., basic skills levels and how they function in interpersonal relationships). Vocational rehabilitation and medical personnel are very likely to have critical information

regarding the student's functional limitations. Engaging all of these individuals at some point in these SSI application processes, will provide the SSA office with a complete and detailed picture of the student. All of this information will assist state Disability Determination Services and SSA staff in determining the student's eligibility for SSI benefits and work incentives. IEP/transition team members and other professionals can also offer their previous knowledge of how to access SSI benefits and work incentives in an efficient manner.

Food Stamps

The Food Stamp program provides financial assistance by enabling recipients to exchange the stamps for food. It is a major supplement for income if an individual with a disability meets the income requirements. This program is federally funded through the Department of Agriculture's Food and Nutrition Service (FNS). It is administered by state and local social service agencies. In most cases, if an individual is eligible for SSI, food stamps will be available too. For more information, contact your local department of social services.

According to Schirm and Castner (2000) the Food Stamp Program is a central component of American policy to alleviate hunger and poverty. The program's main purpose is "to permit low income households to obtain a more nutritious diet . . . by increasing their purchasing power" (Food Stamp Act of 1977, as amended). The Food Stamp Program is the largest of the domestic food and nutrition assistance programs administered by the U.S. Department of Agriculture's Food and Nutrition Service. During fiscal year 2002, the program served over 19 million people in an average month at a total annual cost of over $18 billion in benefits. The average monthly food stamp benefit was about $185 per household.

Although the costs of the Food Stamp Program and other assistance programs are scrutinized during federal budget debates, the Government Performance and Results Act calls for policymakers to pay close attention to the effects of programs, not just total dollars spent. One important measure of a program's performance is its ability to reach its target population. The national food stamp participation rate – the percentage of eligible people in the United States who actually participate in the program – has been a standard for assessing performance for over 15 years. Recent studies have also examined participation rates for socioeconomic and demographic subgroups of the national population (Cunnyngham 2002) and rates for States (Schirm and Castner 2002b).

The U.S. Department of Agriculture (USDA) prohibits discrimination in all its programs and activities on the basis of race, color, national origin, sex, religion, age, disability, political beliefs, sexual orientation, or marital or family status. (Not all prohibited bases apply to all programs.) Persons with disabilities who require alternative means for communication of program information (Braille, large print, audiotape, etc.) should contact USDA's TARGET Center at (202) 720-2600 (voice and TDD).

To file a complaint of discrimination, write USDA, Director, Office of Civil Rights, Room 326-W, Whitten Building, 1400 Independence Avenue, S.W., Washington, DC 20250-9410 or call (202) 720-5964 (voice and TDD). USDA is an equal opportunity provider and employer.

Health Insurance Issues

A great deal of financial, social, and medical support is available within the community, state, or country, but it is up to the parent to wade through the vast amount of terminology, forms, agencies, issues, and so on to find the best direction for a particular child. As a special educator involved in the transition process it is crucial for you to be knowledgeable about all the areas of health insurance that exist so that you can assist the parents in this very important area. The path to the correct resources will differ from family to family as a result of:

- the family's personal financial situation
- the type of available health insurance
- the child's specific medical needs

- the state in which the family resides
- the family's understanding of its rights and responsibilities

Exploring Insurance Options

The importance of exploring all the available options and avenues of assistance cannot be stressed enough; being proactive in this area is essential. The first thing parents need to know is how to locate general sources of medical, financial, and insurance assistance. Through these sources parents will find the best quality health care at the least risk. Following this process can help the family discover several options that may reduce their costs.

Medical care and insurance have gone through major changes in the last five years with the advent of HMOs, or health maintenance organizations. These organizations assist insurance companies by evaluating and authorizing appropriate medical care. The best available medical insurance policy for a child with disabilities may already have been determined by the parent's company's insurance carrier. If the parent does not currently have a policy, or are considering changing their current policy, they will be confronted with many different options. Several individuals and agencies can be contacted for assistance in making this decision. They include:

- the office of social services in the medical facility where the child is treated or cared for
- the primary care physician
- the agent or claims representative in the company with which the parent may have health insurance
- the billing department for a specific physician or medical facility
  the state department of health

When contacting these individuals or agencies, have the parent develop a script beforehand, and keep a piece of paper or notebook handy to take notes on each conversation. They will also have to keep track of offices to which they are referred, insurance policy details, and state support systems.

There are people who can help the parent identify resources in their own community and in their state, as well as help them learn the questions to ask. These people are the parents and care providers who have been there. They can empathize with the complexity of details--phone calls, correspondence, medical forms, financial forms, and lingering questions. It may be helpful to contact parent groups and disability organizations near the school or community to ask for help in research. Associations concerned with specific disabilities can provide helpful information. Even if there is not an association for the child's specific needs, another group whose members also have complex medical needs will have information on financing these needs.

When the parent contacts these individuals or agencies, they will need to offer the following information so that they may give the family the best options for their situation:

- the health care needs of the child
- the family medical insurance situation
- outstanding expenses
- what the family needs

Kinds of Insurance Policies

Before choosing an insurance policy, contact your personnel department, insurance broker, or state department of insurance. You may want to consider one of the following three kinds of policies:

- a health maintenance organization (HMO)
- an indemnity plan
- a preferred provider organization (PPO)

Health maintenance organizations or HMO's represent prepaid or "capitated" insurance plans in which individuals or their employers pay a fixed monthly fee for services, instead of a separate charge for each visit or service. The monthly fees remain the same, regardless of the types or levels of services provided. There is usually a small copayment required for approved doctor's visits. Services are provided by physicians employed by, or under contract with, the HMO. HMOs vary in design. Depending on the type of HMO, services may be provided in a central facility or in a physician's own office.

A health maintenance organization (HMO) is a type of managed healthcare system. HMOs, and their close cousins, preferred provider organizations (PPOs), share the goal of reducing healthcare costs by focusing on preventative care and implementing utilization management controls.

Unlike many traditional insurers, HMOs do not merely provide financing for medical care. The HMO actually delivers the treatment as well. Doctors, hospitals, and insurers all participate in the business arrangement known as an HMO.

HMOs provide medical treatment on a prepaid basis, which means that HMO members pay a fixed monthly fee, regardless of how much medical care is needed in a given month. In return for this fee, most HMOs provide a wide variety of medical services, from office visits to hospitalization and surgery. With a few exceptions, HMO members must receive their medical treatment from physicians and facilities within the HMO network. The size of this network varies depending on the individual HMO (Fidelity Investments, 2003).

When you join an HMO, you choose a primary care physician (PCP) who is your first contact for all medical care needs. The primary care physician provides your general medical care and must be consulted before you can see a specialist. Because of this control system, HMO costs tend to increase less rapidly than other insurance plans.

Indemnity health insurance plans are also called fee-for-service. These plans existed before the rise of HMOs. With indemnity plans, the individual pays a predetermined percentage of the cost of health care services, and the insurance company (or self-insured employer) pays the other percentage. For example, an individual might pay 20 percent for services and the insurance company 80 percent. The fees for services are defined by the providers and vary from physician to physician. Indemnity health plans offer individuals the freedom to choose their health care professionals (Insurance Glossary, 2003).

Preferred provider organizations (PPOs) offer discounted rates if one uses doctors from a pre-selected group. If an individual uses a physician outside the PPO plan, the individual must pay more for the medical care.

Calculated Decisions

Deciding between an HMO, PPO, or indemnity plan is usually based on personal preferences with respect to freedom of choice and one's ability to pay for that freedom. There are medical factors, however, that may influence an individual's informed decision. Parents may also want to consider the following by estimating the expected, predictable health care needs of each family member over the next year:

How many visits to the doctor are expected for such preventive services as childhood immunizations, mammograms, pap tests, or sigmoidoscopies?

Is the individual planning to start a family? Will the child be born in the current year or next?

Is the condition chronic, such as diabetes that requires ongoing medication?

What is the individual's philosophy about medical services and health care professionals?

Does the individual tend to go to the doctor for minor problems that in most cases would clear up on their own?

Does the individual practice medical self-care in attempts to avoid going to the physician?

What was the average cost for health care services for the family over the past two years?

Have the parent/s try to estimate the likelihood of unpredictable health care needs of each family member over the next year. Have the parent ask the following questions:

How healthy have family members been in the past?

Does a member of the family have a chronic condition that requires sporadic visits to a health care professional?

Does anyone in the family smoke?

Does anyone consume more than a reasonable amount of alcohol, that is, according to state standards?

Is the individual sedentary or does he/she exercise regularly?

While answers to the above will not tell you which plan is best for the individual, and his/her family, they can help estimate health care costs over the next year. Then, the family can compare the estimated costs of the various plans to see which plan is likely to be the best.

Medicare

Born out of the 1960s, Medicare was a response to growing concerns about the high cost of medical care for older Americans. Since that time however, the program has expanded to include not only older Americans but millions of adults with disabilities. Unlike Medicaid (discussed later) which is based solely on financial need, the right to Medicare benefits is established primarily by payroll tax contributions. Medicare is a federal health care insurance program that provides some medical coverage to people over 65 and also to individuals with disabilities for a limited period of time. Medicare will help meet some bills for long-term care, but will not fund unlimited long-term care. To meet uncovered costs, you may need supplemental or "medigap" insurance policies. Medigap insurance is offered by private insurance companies, not the government. It is not the same as Medicare or Medicaid. These policies are designed to pay for some of the costs that Medicare does not cover.

Medicare is a federal program that provides health insurance to retired individuals, regardless of their medical condition. Below are some basic facts about Medicare you should know (Fidelity Investments, 2002):

- Medicare coverage consists of two parts--Medicare Part A (hospital insurance) and Medicare Part B (medical insurance). A third part, Medicare Part C (Medicare+Choice) is a program that allows you to choose from several types of health-care plans.
- Medicare Part A (hospital insurance): Generally known as hospital insurance, Part A covers services associated with inpatient hospital care (i.e., the costs associated with an overnight stay in a hospital, skilled nursing facility, or psychiatric hospital, such as charges for the hospital room, meals, and nursing services). Part A also covers hospice care and home health care.
- Medicare Part B (medical insurance): Generally known as medical insurance, Part B covers other medical care. Physician care--whether it was received while you were an inpatient at a hospital, at a doctor's office, or as an outpatient at a hospital or other health-care facility--is covered under Part B. Also covered are laboratory tests, physical therapy or rehabilitation services, and ambulance service.
- Medicare Part C (Medicare+Choice): The 1997 Balanced Budget Act expanded the kinds of private health-care plans that may offer Medicare benefits to include managed care plans, medical savings accounts, and private fee-for-service plans. The new Medicare Part C programs are in addition to the fee-for-service options available under Medicare Parts A and B.

Medicaid

Medicaid is a federal-state program that helps pay for health care for non-elderly people who are financially needy or who have a disability. Individual states determine who is eligible for Medicaid and which health services will be covered. Most people do not qualify for Medicaid until the majority of their money has been spent. It is important to realize, however, that some individuals whose incomes are not in

the lowest category, but who have substantial medical expenses, do qualify for Medicaid. These individuals--who either have incomes higher than the AFDC (Aid for Families with Dependent Children) cut-off or have very high medical bills that drop their incomes below the level established for "categorically needy"--are termed "medically needy." Once an individual is covered by Medicaid, he or she is entitled to receive the following minimal services:

Physician services
Laboratory and X-ray services
Outpatient hospital services
Skilled nursing facilities (SNF) for persons over 21
Family planning services
Medical diagnosis and treatment for persons under 21
Home health services for individuals
Inpatient hospital service
In many states, Medicaid will also pay for some or all of the following:
Dental care
Medically necessary drugs
Eyeglasses
Prosthetic devices
Physical, speech, and occupational therapy
Private-duty nursing
Alternative medical care, for example, chiropractors, acupuncturists
Diagnostic, preventive, screening, and rehabilitative services
Inpatient psychiatric care

Federal law dictates that states may not reduce other Welfare benefits people receive when they become eligible for Medicaid. Also, states may not impose citizenship or residency requirements other than requiring that an applicant be a resident of the state. Neither the age of the applicant nor the fact that he or she works are restrictions to receiving Medicaid.

Since its inception, the program has been plagued by fraud from both health care providers and patients. To curb these, Congress passed a law in 1996 making persons criminally liable for committing fraud in order to become eligible for medical assistance (Legal Information Institute, 2003).

Medicaid Waivers

Waivers are intended to provide the flexibility needed to enable states to try new or different approaches to the efficient and cost-effective delivery of health care services, or to adapt their programs to the special needs of particular areas or groups of recipients.

A waiver under Section 1915(c) of the Social Security Act allows a state to include as "medical assistance" under its Medicaid plan home- and community-based services furnished to recipients who would otherwise need inpatient care that is furnished in a hospital, skilled nursing facility, intermediate care facility, or intermediate care facility for individuals with mental retardation (ICF/MR), and is reimbursable under the state plan (Assistive Technology Partners,2003).

Each state determines which services will be reimbursed by Medicaid. If you have any questions, contact your local social services agency.

Beginning in 1981, states have been able to obtain formal permission from the federal Medicaid agency (HCFA--Health Care Financing Administration) to set aside typical Medicaid restrictions. This permission allows for services to be provided in the home or community to certain individuals who would otherwise have to be institutionalized in order to be eligible for Medicaid.

Now in states with Medicaid waivers, children can stay at home when medically possible and, under certain conditions, not have their parents' income deemed (counted as belonging) to them. Also, under some waivers, some nonmedical services, such as respite care (discussed in Chapter on Residential Opportunities), may now be covered by Medicaid.

The types of Medicaid waivers include the following:

• Model Medicaid Waiver: Under this provision, states apply to the federal government for waivers before they can cover services traditionally covered by the Medicaid program in that state for persons who would have to be institutionalized. The requirement to consider income is waived to allow medically eligible persons to qualify for this program. Each state defines requirements for eligibility.

• Home and Community Based Medical Waiver: Under this provision, states who apply to the federal government for waivers can cover services typically financed under Medicaid (as the Model Medicaid Waiver does) and go beyond to cover additional services in the community. These additional services are identified as "waivered services" in the community. Home- and community-based waivers are available for certain categories of individuals who otherwise would be institutionalized and who meet qualifications specified by the state for this waiver.

• State Medicaid Plan Option: Another strategy states can use to help families become eligible for Medicaid is to amend the state plan. With this approach, states can provide, without obtaining special permission from the federal government, medical services to certain designated categories of children who would otherwise be institutionalized or hospitalized. Instead, a state plan, approved by the federal government, certifies categories of children who meet these qualifications.

Conclusions

Dealing with the issue of entitlements is often frustrating, but it's important to persevere. For specific information about the benefits provided through SSDI and SSI contact your local Social Security Office (listed in the telephone directory under "Social Security Administration") and request a copy of the publications addressing SSI and SSDI. Single copies are free. You can also contact the SSA through its toll-free number: (800) 234-5772 (voice) or (800)325-0778 (TDD); it is available 24 hours a day. Because of the volume of inquiries that SSA receives, it is best to call early in the morning or late in the afternoon. SSA also recommends calling later in the week.

Remember, not every service is available and not every person can be helped 100 percent. Keep in mind that every year new programs begin and some old ones end, particularly at the state and local levels. Have your students and their parents keep in touch with their contacts and stay as aware as they can, through reading and talking to knowledgeable people about what is happening in the area of services for individuals with disabilities. There are many excellent voluntary organizations as well as state, local, and federal offices that can help you. Numerous newsletters are produced by groups of and for individuals with disabilities. Using the Internet can connect people to much information and innumerable resources.

One of the major aspects of coping with a disability is educating oneself about both the disabling condition and what is available to enhance one's quality of life. Initially, the task of acquiring information falls to the families and the professionals they encounter. This information, however, must be passed on to the young person so that, as much as possible, he or she can achieve a satisfying independent life.

As of the spring of 1996, vast changes have been made in the Welfare Reform Act. Consequently, each state is in the process of revising its legislation in accordance with the new federal guidelines. The ultimate effect will not be known for some time. It is clear, however, that in many cases, benefits will be diminished. Each individual situation should be explored with the local Department of Social Service and Social Security Administration.

Because of these changes, this may be a time to help the student and his/her family become proactive, or to renew their commitment to advocate for the needs of their family and community.