

(Social Security continued)

to eighteen years of age, and disabled offspring of any age--including adults--are likely to qualify for Social Security benefits upon their deaths.

Family members, including disabled children, who qualify for Social Security benefits on a worker's record need not have contributed on their own to receive benefits.

HOW DOES SOCIAL SECURITY DISABILITY INSURANCE (SSDI) WORK ?

Social Security Disability Insurance (SSDI) is the federal worker's insurance program which provides monthly cash benefits to disabled workers and their dependents. Disabled offspring are also likely to be eligible for this benefit through the retirement or deaths of their supporting parent(s).

To qualify for SSDI, a worker must have worked a long enough period of time and have been recently covered under Social Security. The Social Security Administration (SSA) interviewer will make that determination at the time of application.

However, to be sure your family benefits fully from this entitlements program, you must notify the Social Security Administration of the parent's disability, retirement, or death, and inform SSA that the family also includes a developmentally-disabled child or adult.

Eligibility for Social Security Disability Income is based on the individual's inability to work; having the disability does not, by itself, entitle people to the benefit.

Employment, including sheltered workshop employment, does not immediately disqualify your sibling from receiving SSDI, but his/her income will be counted in determining continued eligibility.

You need not be the legal guardian to apply for SSDI on behalf of your sibling--anyone may file the application--but processing may take two to three months.

WHAT IS SUPPLEMENTAL SECURITY INCOME (SSI)?

The Supplemental Security Income(SSI) program, begun in 1974 by the Social Security Administration using general tax revenues, pays monthly benefits to people in financial need who are 65 years of age and older, blind, or disabled in other ways. This program covers many of our brothers and sisters.

SSI is meant to supplement income from other sources--including contributions (room and board usually)--made by a parent or relative with whom the disabled person lives, and so the monthly entitlement varies from individual to individual.

Disabled individuals--including children--living at home, with siblings, or in residences, may be eligible for SSI. Remember that this entitlement is needs-based--assessed according to the income and resources (assets) of the applicant, or if he/she is under 18, the income/resources of the entire family.

Like SSDI, eligibility for Supplemental Security Income is based on the individual's inability to work, but with SSI, financial need must also be shown. Income from employment, even if sheltered workshop employment, does not disqualify your sibling from receiving SSI, but will be counted in determining the amount of the entitlement.

REPRESENTATIVE PAYEE

A "Representative Payee" is a person--not necessarily a legal guardian--who has informed the Social Security Administration that he/she will be responsible for managing the cash benefits of a disabled individual receiving SSDI or SSI who is unable to handle finances independently.

Unless your sibling is living in a residence such as an ICF(Intermediate Care Facility) or CR (Community Residence) or IRA(Individual Residential Alternative) in which the non-profit agency which runs the program is the representative payee, you or other members of your family may apply for this "position." As a "rep payee," your responsibility is to keep yourself informed of your sibling's needs so you can decide how the benefits can best be used. Social Security will ask you, periodically, to fill out a report explaining how the entitlements are being used, and you will be responsible for reporting any changes in your sibling's income or resources. **This position is a serious one.** The representative payee is personally responsible for reimbursing the government for any overpayment made to the disabled person.

WHAT IS MEDICARE?

Medicare is the nation's only federal health insurance program. Financed by taxes, Medicare assists people receiving Social Security to pay for hospitalizations, skilled nursing facilities and outpatient physician and related services. Premiums are deducted from recipients' Social Security checks, and 80% of allowable health costs are covered by the program.

If your sibling is receiving Social Security Disability benefits (SSDI), he/she will become Medicare-eligible 24 months from the date of their eligibility for SSDI.

Medicare provides basic protection against major medical expenses. It does not, however, cover a complete range of health care costs. Since Medicare pays higher physician fees than does Medicaid--and your sibling may be eligible for both Medicare and Medicaid--you are likely to have a far wider range of providers to choose from with Medicare. Again, you should check with the individual providers to see which coverage they accept.

WHAT IS MEDICAID?

Medicaid is a government assistance program which pays for a comprehensive range of medical services for people who have low incomes. The program is supported by both federal and state funds, and is administered by the New York City Department of Social Services.

If your brother or sister is receiving SSI, he/she is eligible for Medicaid, and should automatically receive the Medicaid card.

If your sibling does not meet SSI eligibility criteria, then eligibility for Medicaid will be determined by his/her level of income and other resources, and an application must be filed.

Note, however, that since the fees Medicaid pays to physicians are quite low, many doctors do not accept the Medicaid card. Check with the individual physician as to whether he/she will accept Medicaid payment or call the Medicaid Provider Number for a list of physicians who do see Medicaid patients.

Special Alert for Medicaid Recipients:  
New York State is encouraging Medicaid recipients to change to a Medicaid Managed Care Plan. This is a voluntary choice, not mandatory. Get more information before making any changes.

WHAT IS THE MEDICAID SURPLUS INCOME PROGRAM (SIP)?

If your brother or sister is not Medicaid-eligible through SSI and his/her net monthly income is above the Medicaid limit, Medicaid coverage may still be available through the Surplus Income Program. Through SIP, assistance may be obtained in paying for medical bills. SIP eligibility is re-determined each month based on the size of your sibling's medical bills relative to the amount his/her income exceeds Medicaid's monthly income limits. The re-determination process is somewhat tedious, but depending on your sibling's situation, SIP may be worth looking into.

FAMILY SCENARIOS

Situations From The AHRC NY Sibling Meetings

Practical advice: Here are some of the lessons adult siblings who attend the Sibling Support Group meetings have learned.

Lesson #1: Eligibility for benefits/entitlements does not automatically mean you will receive them even if you/your sibling applies. Several members of the Group or their families have "counted" on benefits that they apply for. Not always true. Which brings us to our second Lesson from Experience:

Lesson #2: Don't assume that someone who is eligible for benefits and receives benefits and is then deemed ineligible and denied benefits will eventually have his/her benefits restored. It is sometimes difficult to secure benefits your family member is entitled to; it will be even harder to get them back if you lose them. You must never assume anything in the entitlement system. Several families in our Group have made decisions, including employment decisions, based on the knowledge that though they might lose a particular benefit, they will certainly be able to restore that benefit at a future date. To their surprise and great stress, it proved harder to get the benefit back once they had been deemed ineligible or denied that benefit--in several cases, those benefits never were restored. Try not to make adjustments that you know are short-term if the consequence is that your family member loses benefits that you think that person may need in the medium or longer term.

Lesson #3: Err on the side of caution when dealing with the

SIBLING MEETINGS ARE SCHEDULED MONTHLY ON SUNDAY AFTERNOONS. CALL AHRC FOR SPECIFIC DATES.

entitlement system. Assume that the effort will be difficult, time-consuming, and require patience and possibly expertise.. Consider hiring an advisor who has successfully negotiated whatever system it is that you are involved with. Be as cautious as you can afford to be. Try not to wait for a crisis.

Members of our Group are consistently surprised by how long it can take to secure benefits and to appeal if benefits are denied a family member. Needless to say, in a crisis, it is hard if not impossible to proceed with all deliberate speed. Please remember that most systems do not consider it a responsibility to help you secure benefits without careful and full consideration of the application. "90 days can be considered a quick application turnaround," said one frustrated Group member, "and I was still dealing with the system 18 months later." That can lead to significant frustration, not to mention stress.

Lesson #4: Be prepared, anticipate, and plan, plan, plan. If there is one lesson that our Members have learned repeatedly, it is that you should never go into a process of trying to secure benefits without being prepared. Try to find someone (see the resources section of this newsletter or consult the advisor we recommend in Lesson #3) who knows the system and has been through the process before so that you can prepare for some of what may be asked of you. NEVER "WING" IT and NEVER OFFER INFORMATION if it is not requested. That information may turn out to be wrong, and that could deprive your family member of benefits, and /or at the least delay the processing and consideration phases of getting the benefits.