

A lesson the Group wants you to know: imagine the unimaginable. Plan what you will do if *benefits don't come through* for a year. What you will do if your family member is *denied* benefits. It may be no more than, as one Group member said, "I will plan to have a nervous breakdown!" You can't always depend on systems coming through when you need them. If you understand that this is a possibility, it won't be quite as difficult to deal with.

Lesson #5: Many benefits are dependent on the individual's income and/or asset levels. Even temporary increases in an individual's income levels can reduce the level of benefits—sometimes temporarily, sometimes permanently. If your sibling is on benefits now, ask how each will be affected by a rise (or fall)—even a temporary "windfall"—in his/her income. There may even be rules limiting the income the person can depend on from the family. An additional piece of advice from one Group member: make sure you know the rules for gifts of cash to individuals living in residences. Temporary bulges in income sometimes lead to reviews about whether this income can be counted upon by the resident all the time.

Lesson #6: Certain types of disabilities can make eligibility and securing a safety net of entitlements for your brother or sister more difficult. Our Group members have found that benefits can be difficult to obtain or keep for siblings who 1) have a dual diagnosis of mental health problems and mental retardation - and/or 2) are higher functioning. Some eligibility determinations rely heavily on "simple" indications of disability, such as IQ level. Functioning level, which is harder to measure (involving traits such as "too trusting", "incapable of handling money", "emotionally volatile") may be even more important in defining your sibling's disability. If your sibling is considered higher functioning be sure that you have documentation accurately expressing how well (or poorly) they function independently.

Similarly, when the diagnosis is complicated or multiple, secure as much documentation on each of the specific problems that your brother or sister has.

Lesson #7: One of the most problematic areas and sometimes impediments to trying to secure benefits can be if a brother or sister is employed. Often our siblings or our parents benefit a great deal from a sibling's employment. The disabled sibling gets great self esteem and confidence from working and parents who are older may be dependent upon that income to keep a family home or put food on the table.

Group members recommend that you be very cautious when your brother or sister is considering competitive employment as opposed to sheltered work. Make sure you know what impact the income from the job will have on benefit levels and entitlements. Think about whether there are any other services that you or your parents or your sibling had been contemplating applying for. Make sure you know how any application will be affected by current employment income. This is actually a fairly horrible dilemma that our Group members have faced: a disabled sibling who thinks he/she needs to earn money to be "worth" anything in part because of outside messages that value paid work so highly; and/or parents who "need" the income to keep an aging family together. Often those immediate needs seem more tangible than the potential of losing benefits which might happen down the line. Group members recommend that you enlist the support of a social worker or other supportive professional; that you determine exactly what the impact of employment on your sibling's present or future benefits might be especially if it means the loss of benefits as essential as health care. If our Group's lessons tell you nothing else, it is that benefits and entitlements should not be applied for, fought for, nor taken for, granted!

HELPFUL HINTS :

Telephone Numbers

SOCIAL SECURITY (SSI, SSDI)

For location of your local Social Security office, call the Social Security Administration hotline: 1-800-772-1213

MEDICAID

For borough office locations, call: 1-718-291-1900
Note: This number also provides access to recorded information about Medicaid and other benefit programs.

MEDICARE

For information call:
1-800-442-8430

A.C.E.S. Advocacy, Counseling, and Entitlements Services

This program provides consultation services to assist individuals in accessing benefits and entitlements. For information call:
212-614-5552

The information in this Bulletin is for general use only. We recommend that you contact your family lawyer or professional advisor in regard to your individual situation.

ENTITLEMENTS : QUICK TIPS

1. **File at your local Social Security office.** If you file in an office outside your area, the file will be transferred back and processing will be delayed.
2. **Must Do:** If you deliver documents or applications by hand or by mail, **always make copies for yourself.** When you mail **always send "Certified Mail / Return Receipt Requested"**. Whenever you discuss your case with a representative of an agency **always note the day, time, name and position of that person.**
3. **Come prepared with accurate information** when applying for benefits. It's the key to a successful interview. Types of items to bring with you on the first visit are birth certificate and proof of address. Call ahead: requirements vary. Documentation of the disability (IQ and other psychological assessments) should be reviewed carefully with your advisor before submission.
4. **Establishing a good rapport between yourself and the interviewer is helpful, but do not expect this to effect decisions.** As unique as your situation feels to you, many of the criteria for eligibility are fixed and not open to discussion. Don't approach an application process as going into battle. If you get a hostile interviewer politely ask to speak to a supervisor and calmly tell the supervisor why you would prefer to be interviewed by someone else.
5. Decisions can be appealed. **But you must appeal within the time limit** (usually 10 days). Your appeal can be denied if you are even one day late. An appeal is an adversarial situation. You should have an attorney with you at a hearing.
6. If you are a SSI (Supplemental Security Income) recipient, you are automatically MEDICAID eligible. You do not have to apply for Medicaid. You do not have to submit an annual Medicaid recertification.
7. When applying for SSI, **always request a Protective Filing Date.** This will assure that your filing is recorded on the date you requested the appointment, even if it was over the phone, which may be weeks before the actual visit.
8. The fact that you are the legal guardian of your brother or sister does not entitle him or her to Social Security Survivor's Benefits upon your death.
9. MEDICARE and MEDICAID are entirely different programs. Medicare is an **insurance** program, Medicaid is an **assistance** program.
10. Seriously consider using an attorney experienced in Social Security and entitlement issues. Fully understanding these complex issues can be crucial to your sibling's financial security and to his/her ability to obtain health insurance.

Do you have a family member, friend, or acquaintance with a developmentally disabled brother or sister who would like to be on our mailing list?

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