

SIB

SIBLING INFORMATION BULLETIN

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AHRC NEWYORK

FALL 1997

HEALTH & HEALTHCARE

I. Introduction:

In helping our developmentally disabled siblings keep healthy and access good health care, AHRC's Sibling Network members believe our responsibilities include the following: to become knowledgeable about our siblings' health problems and to see that other caregivers do the same; to hold health care systems responsible for meeting our siblings' health needs; to assure that our brothers and sisters remain as comfortable and pain-free as possible; and to help maximize health enhancing program and treatment choices, making sure to include our siblings, where possible, in making those choices.

In the health care area, we have much in common with our siblings: we all get sick from time to time, feel anxious about illness and treatment, we all age, and we all have occasional difficulty in communicating with providers. However, unlike our siblings, we can rely on our own, often substantial, abilities and resources to negotiate health care systems.

Our siblings' lack of "purchasing power" limits their access to medical care. Many of our siblings pay for health care with Medicaid, and Medicaid payments are far lower than private-practice physicians usually charge. Moreover, the skills healthcare providers rely on to communicate frequently don't work with our siblings. Our handicapped siblings may not be reliable about reporting where it hurts, for how long it's been hurting, whether the medication is helping, etc. So, appointments may take longer, diagnoses are more difficult to make, and treatments harder to monitor.

The financial and communication issues may be compounded by the fact that many of our siblings have multiple physical problems and perhaps mental health problems, like depression or substance abuse, as well.

II. Choosing a Health Care Provider

General Medical Care

If you are beginning your search for a physician for your sibling, think about establishing a *long-term relationship with a caring practitioner*. The following are some tips to help you find a physician or other medical provider.

- Consider finding a family practitioner for your sibling. Family practitioners are physicians trained to think about the complete range of the individual's needs--psychological, nutritional, physical activity levels, etc. and to work with a wide variety of populations.
- Physicians who have nurse practitioners (NP's) and/or physician assistants (PA's) working with them may also be a good bet, since these non-MD providers frequently care for the time-consuming patients the physician can't. By law, NP's and PA's are supervised by physicians, so you should not, by and large, worry about the extent of their knowledge.
- If you have a physician or other provider with whom you have a good relationship for your own health care, you will probably find that person willing to see your sibling. However, you will need to spend some time at your sibling's appointments to facilitate communication--certainly in the short run, and possibly on an on-going basis. If you or your sibling's caregiver can spend time to facilitate your

sibling's relationship with the provider, the provider can then use his/her time to make an accurate diagnosis and thorough treatment plan.

- If your sibling has Medicare, be sure you mention this to a prospective provider. (Your sibling may be eligible for Medicare if his/her parent or guardian has a substantial work history, and your sibling's disability began before the age of 18).
- Finally, use your sibling's service agency(ies) for provider recommendations. At AHRC, you can contact the Family and Clinical Services Department, which has been compiling a list of providers used by AHRC clients/families.

Specialized Clinics

There are a number of specialized clinics serving the developmentally-disabled individuals throughout the New York area. Examples are the clinics at Roosevelt Hospital, Terence Cardinal Cooke and Stuyvescent Polyclinic (part of Cabrini) and AHRC in the near future in Manhattan, the Urban Health Plan and the Kennedy Center in the Bronx, Maimonides Developmental Center in Brooklyn, the Westchester Institute for Human Development in Valhalla.

There are advantages to using special clinics: Supervising providers and administrators have a great deal of interest in our siblings, are experienced in their care, and are likely to be responsive to special needs and problems, and the clinics accept Medicaid, Medicare and sliding-scale fees.

Managed Care

Under a Managed Care system, you and your sibling will probably have to choose a physician, called the primary care provider, to keep track of and coordinate all necessary medical and psycho-social services. Managed Care's growth is due to the expectation that the primary care provider's careful allocation of services to his/her patients and the emphasis on preventative care will keep costs down. While many Medicaid-eligible patients are required to "sign up" for managed care, for the near future our developmentally disabled siblings have been exempted.

Managed care's helpful features include: written contracts specifying the services you/your sibling are entitled to, formal appeals processes to be followed if coverage is denied for a service you wish, an emphasis on preventative services--routine exams, screenings, and health education--and very importantly, availability of case managers for special needs patients. (Case Managers can partner with you, your sibling and the provider in determining your sibling's health service needs.)

- Having a good relationship with your primary care provider is the most important factor leading to success in your managed care plan--or to success with your provider regardless of insurance system. Do not be afraid to shop around for one who is comfortable with your sibling's needs. In cases of appeals for denied coverage, the primary care provider has a great deal of influence in overturning a decision.

III. Special Needs To Think About

Sibling Network members can't overemphasize their importance as "communication enhancers" in their siblings' relationships with providers. Assuring that our siblings first "tell" us or other caregivers all they know helps improve their chances of appropriate, timely, and sensitive care.

- If your brother or sister is not fluent in English or is non-verbal, good care requires that medical professionals be "briefed" regarding his/her "language."

Of particular importance: a behavior that means something else. For example, what appears to be a smile may actually be a grimace of pain. Don't hesitate to ask that your sibling's "special" or first language be noted in the medical chart and/or posted on the hospital-room wall. Consider asking the hospital social worker or patient advocate to help provide "translation." Caring, responsible professionals will want to know.

- You may need to arrange for someone who knows your sibling to remain with him/her throughout a medical procedure or hospitalization. AHRC routinely assigns staff to the hospital bedsides of its residential clients; request other agencies to do the same.

Even if your sibling can communicate, he/she doesn't always know what is important to convey, including what may be an important disease symptom.

- So, to be sure problems are

detected early, you or another advocate or caregiver may need to listen closely, ask the right questions, and see that all issues, even apparently irrelevant ones, are raised during exams for illness or injury, and at routine physical or dental check-ups.

- Alert as many people as possible to the "facts" about your sibling. A medical identification bracelet or tag or a medical alert card is useful if your brother or sister travels alone.

If your sibling is lost, becomes disoriented, or has an accident, clear information on a medical bracelet or tag can quickly alert strangers to his/her special status.

- Be alert to behavior changes in your sibling, and "brainstorm" along with his/her other caregivers, about possible causes or precipitating events.

Behavior changes may come about as a result of stress or aging or their interplay. Our siblings may be stressed over situation that wouldn't stress us, or they may begin to show effects of accumulated stress, or to change their expression of stress over time. Network siblings have seen brothers and sisters develop stress reactions in competitive employment situations, particularly as they get older. Some have siblings who were performing well in supported, competitive, or workshop employment, suddenly became quite anxious.

Physical illness or medication side effects can also cause behavior changes. And finally, consider the possibility of drug

or alcohol abuse. Is there an unexplained change in your sibling's behavior? (see "Dual Diagnoses" notes below.)

Sometimes our siblings age faster than we would expect. Although age is not necessarily associated with poor health, aging or health concerns may call for changes in your sibling's routines and activities. He/she may, for example, need help to develop new hobbies or exercise programs if old ones become too stressful or strenuous. Note that reliance on additional medication is probably a less preferable choice than program/lifestyle changes for our siblings. If your brother or sister lives in a residence, be sure to discuss "lifestyle" issues with staff.

Sometimes, as with the rest of our family and friends, there are no good medical choices. Some choices that might work for other people don't work for our developmentally disabled brothers and sisters. Pain, procedures that are frightening or incomprehensible to our siblings, heroic measures, overly aggressive or overly passive medical interventions--are all fraught with extra dangers for our brothers and sisters.

IV. Caring or Overseeing Care For Your Sibling

Whether you or another family member or guardian is caring for your sibling or he/she is living in a community residence, consider the following to help keep the medical situation under control:

- Maintain a binder containing your sibling's medical information: his/her history, including allergies and hospitalizations, copies of lab reports, current providers' names and specialties, medications and dosages, contact people at the various provider offices, and appointment dates. Other information, such as a copy of your guardianship statement and any "advanced directives," see below, should also be kept in the medical binder.

Network members encourage you to make several copies of medical information to increase "emergency preparedness" among your family members.

- Remember that as guardian, you are entitled to receive copies of your siblings' medical records, lab reports, etc.
- Use your *pharmacist!* Ask for the consumer information sheets available with each prescription medication. The sheets let you know the medication's purpose, dosage, how it is to be taken, for how long, precautions and the side effects. Keep them in your medical binder.
- Make sure you have the name of a contact person--perhaps the person who makes appointments--at the provider's office or clinic. It helps to establish a relationship with this person as well; if an emergency occurs, he/she may be helpful in getting through to the provider.

If your sibling lives in a community residence, it's a good idea to keep in contact with the case manager or staff person charged with his/her medical care regardless of the amount of care

required. Find out what's doing, go to occasional medical or dental appointments, make some personal contact with the provider(s), and generally keep "on top of things." As a family member and/or guardian, you are part of the program planning team; staff should welcome your assuming some responsibility for obtaining good health care for your sibling.

Hospitalizations

Learn the names of the nurses who have been assigned to care for your sibling on the various shifts, and make contact with at least some of them to facilitate relationships with your sibling. And, get the phone numbers of the nursing station, and make sure the clerk at the station has your name and numbers.

Use the patient advocate if things go wrong or just to alert him/her that your sibling is a "special needs" patient. The advocate is frequently someone who can cut through hospital bureaucracy; you may want to give him/her your telephone numbers.

If you are able to remain calm and perceived as helpful, hospital rules such as visiting hours may be stretched for you.

Treatment Decisions: You may need to get several professional opinions regarding a sibling's surgery or other treatment (remember that a surgeon's treatment is usually surgery!) Your sibling's provider may not understand the ramifications of a procedure for someone who has multiple problems, cannot speak up about how things are going, or has limited after-care options.

Make sure you understand treatment, anesthesia, and medication options, including potential outcomes, complications, and side effects, and the likely short and long-term effects on your sibling.

Speaking with other families who have gone through similar situations may be helpful to you. Contact the AHRC and/or other agencies caring for your sibling to help with making medical decisions, and perhaps to put you in touch with other similarly-situated families.

Informed Consent: If your sibling has an emergency, a provider will perform a procedure considered absolutely necessary. However, in a non-emergency situation, a parent or guardian must consent to a procedure if the provider feels that your sibling is not capable of understanding its risks, benefits or consequences. One of the most compelling reasons to obtain *legal guardianship* is the guardian's ability to give timely, informed consent to health care decisions.

Surrogate Court Decision making: In cases where there is no parent or legal guardian to give informed consent, a provider may need to obtain consent via a court order. As an alternative, in some counties of New York State, a provider may seek legal consent from a Surrogate Court Decision making Panel, comprised of a family member, legal, health care and mental health care providers.

However, this panel is no substitute for the consent provided by a family member who is

familiar with the individual with developmental disabilities.

Advanced Directives:

These express an individual/family/guardian's wishes regarding specific treatment decisions. For example, a "Do Not Resuscitate" order is an advanced directive.

More information and/or assistance about guardianship and advanced directives may be obtained from AHRC's Legal Services Coordinator, from legal offices at other service agencies, or from private attorneys.

Home Care

When the caretaker of a disabled person or the disabled person him/herself needs assistance during a period of recuperation following injury, illness, or surgery, or additional help is required for any reason, in-home care for part-or 24-hour days may be required.

There are many home-care agencies serving the public. However, AHRC now operates a home care service staffed by caregivers experienced with developmentally disabled people. Caregivers are available in all five boroughs, services range from personal care to social work, respiratory and physical therapy, and fees may be paid by public or private health insurance, or sliding scale. Remember too, to take care of yourself if you are caring for a disabled sibling recuperating at home. Consider using AHRC or other agency's *in-home respite care* to help you get some time away from a stressful situation. (see SIB issue on RESPITE & RESIDENTIAL SERVICES)

V. Mental Health & Developmental Disabilities (Dual Diagnosis)

Many of our siblings have secondary diagnoses of psychiatric problems--depression, anxiety, or phobias, or they may exhibit "challenging" behaviors--which can limit opportunities for community activity and create stressful situations for caregivers.

Treatment for psychological/behavioral disorders include analysis of the problems or behaviors followed by one or more of the following: behavior modification programs to teach more appropriate behaviors, redesigns of the physical environment, medications, and "talking," play, art, or music therapies.

Agencies caring for our siblings, such as AHRC, offer psychological and psychiatric services, both at program sites, and, if necessary in home or residences. AHRC also offers a unique outpatient program specifically designed to treat developmentally disabled individuals who abuse alcohol and/or other substances.

If your brother or sister is dually diagnosed, it doesn't mean that he/she will have no physical problems--but understand that service needs and emphases may shift over time. Getting the right "balance" when your sibling has a dual diagnosis is not easy and rarely permanent. Remember to pay attention to adverse effects of your sibling's medications, both psychiatric

and non-psychiatric, and to report them to the provider; and note that mental health problems may be caused by undiagnosed medical conditions. You may need to prepare yourself to help "solve" medical and/or behavior problems many times over.

- Access mental health services for your sibling through AHRC or other agency providing services to him/her; obtaining care through the mental health system is much more difficult than through the developmental disabilities system.

VI. Dental Care

As with medical care, good dental care for your sibling may be hard to find. The same issues may present themselves: our siblings' communications difficulties, psychological issues such as anxiety and fears, the frequency of medical problems which may affect treatment approaches etc. Also, Medicare does not cover dental care, and you may have difficulty finding a dentist who accepts the low Medicaid fees.

There are some clinics experienced in serving developmentally delayed children and adults. These include the NYU and Beth Israel Hospital Dental Clinics in Manhattan, and the St. Barnabas Hospital Dental Clinic and the Kennedy Center in the Bronx. Get recommendations of dentists from AHRC and other caregiving agencies, other families, and perhaps your family dentist.

Keep in mind the importance to your sibling's dental care of regular check-ups and on-going

dental hygiene, and if your sibling is able to understand, hygiene education.

VII. Health and Wellness

Preventative care--check-ups, screenings, health education, etc.--may be more important than you might think. Network members have had siblings' medical problems "uncovered" as a result of routine check-ups.

When you consider "wellness" for your sibling, think about the same issues you may be thinking about for yourself: proper diet, exercise, use of vitamins, vacation breaks from routine, stress reduction exercises, etc.

Schedule a "Wellness Assessment" for your sibling through AHRC's Department of Family and Clinical Services. This new service is designed to assess the health status and needs of the whole person--especially his/her lifestyle patterns and activities, with a view toward determining risk areas and teaching healthier lifestyles.

If your sibling lives in a community residence, raise health and wellness issues with caregiving staff. Too often, the non-crisis aspects of care-taking don't get enough scrutiny.

VIII. Long-Distance Care

If you are overseeing your brother or sister's care "long distance," here are some ideas and suggestions from siblings who have "been there:"

- *Establish guardianship* so you'll be able to make health

care decisions on your sibling's behalf.

- Consider hiring a local advocate for your sibling if he/she is medically fragile, or is undergoing frequent health crises or transitions.

A local advocate might be a family friend, an interested party associated with a local advocacy or quality assurance program, or a medical professional, such as a nurse. This person, or persons, if you prefer more than one, will serve as your local "eyes and ears." For example, if you receive an emergency call in the middle of the night and can't get to the residence quickly, your local advocate could help you assess the situation and comfort your brother or sister until you arrive or until the situation stabilizes.

- Be as familiar as possible with the basics of your sibling's current medical situation and related problems.

• Maintain your medical binder even if your sibling is out of town, making sure that copies of all documents, especially regarding guardianship and advanced directives, remain with your brother or sister's local caregivers and advocates. Remember to include tips about communicating with your sibling and/or interpreting his/her "language" (see Section III above.)

- If you have advanced directives, make sure you know how they are applied in your sibling's state of residence. For example, states may impose different requirements on long term residences, ambulance

companies, and hospitals with respect to honoring "Do Not Resuscitate" (DNR) orders, and you may need to designate a particular ambulance service or hospital you would use in an emergency.

- Don't assume you can just "step in" for emergencies. Keep in touch with your sibling and/or his/her caregivers, case managers or social workers regularly, learning about his/her health needs and encouraging all involved to pay attention as well. Knowing what your sibling's life is like on a daily basis helps you to detect changes that might require medical intervention and encourages staff to be honest and communicative with you.

- Try to meet your sibling's medical care team (doctor, dentist etc.) when you visit, even if it takes time away from activities you/your sibling have planned. Having faces to put with names makes for a more effective medical team.

- If you can, set aside some money for use during an emergency situation. Long distance phone calls, transportation, and other unexpected expenses for your sibling add up. Emergency anxiety and stress are bad, but financial stress makes everything worse.

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IX. Some Final Advice

Come to AHRC Adult Sibling Support Group if you want to think through or talk over healthcare or other issues with siblings who have gone through or are going through similar situations. Call AHRC's Sibling Services Manager at (212) 780-2592 for more information.

Try not to do it alone! Whether your sibling is living with you or your parents or in a residence or supported apartment, there are other caring people who know your brother or sister and can share in

talking over, making decisions about, or overseeing his/her care. The more people who know the basics about your sibling, the more people will be there to help you and your family.

AHRC Sibling Services
Manager
(212) 780-2592

AHRC Department of
Family and Clinical
Services
(212) 780-2603

AHRC In-Home Respite
(Unit Manager)
(212) 780-2509

AHRC Over-Night
Respite
(212) 780-2605

MAILING LIST: Do you have a family member, or know someone with a developmentally disabled sibling who would benefit from being on the mailing list? Send their name and address to AHRC.

Name _____

Address _____

City _____ State _____ Zip _____

AHRC's Sibling Program sponsors a monthly Adult Sunday Sibling Support Group. For the a schedule and information, call Dr. Randy Martin (212) 780-2592.

Only \$10 Will Make You a Member of AHRC



Important Telephone Numbers

Roosevelt Hospital
429 W. 59th St.
NYC 10019
(212) 523-4000

Terrance Cardinal Cooke
1249 5th Avenue
NYC 10029
(212) 360-1000

Stuyvescent Polyclinic (Cabrini)
137 2nd Avenue
NYC 10003
(212) 674-0220

Urban Health Plan
1070 Southern Blvd.
Bronx, NY 10459
(718) 589-2440

Maimonides Developmental Center
(Brooklyn)
4802 10 Avenue
Brooklyn, NY 11219
(718) 283-6000

Westchester Institute for Human
Development in Valhalla
(Westchester County)
Westchester County Medical
Center
WHID
Cedarwood Hall
Valhalla, NY 10595
(914)285-8150

For Dental Care:

New York University Hospital
Dental Center
345 East 24th Street (corner of 1st
Ave.)
New York, NY 10010.5
(212) 998-9873
(212) 998-9457

Beth Israel Hospital Dental Clinic
1st Avenue @ 16th Street
2nd Floor in the Silver Building
New York, NY 10003
(212) 420-2720

St. Barnabas Hospital Dental Clinic
183rd & 3rd Avenue
Bronx, NY 10457
(718) 960-6628

Rose F. Kennedy Center for
Research in Mental Retardation
and Human Development Albert
Einstein College of Medicine
Yeshiva University
1410 Pelham Parkway South
Bronx, NY 10461
(718) 430-4228

YAI Dental Clinic
460 W. 34th St. (between 9th &
10th Aves.)
11th Floor
New York, NY 10001
(212) 273-6142

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