

SIB

SIBLING INFORMATION BULLETIN

Vol. 4, Number 1

AHRC New York City

Fall 1998

ADVOCACY

INTRODUCTION:

The Sibling Committee has put together this bulletin to help you become a more effective advocate for your brother or sister. Whether you're trying to problem-solve around a difficult issue with your sibling's service providers or you've decided to become involved in on-going "community" (i.e. our community of parents, professionals, siblings, and friends of handicapped individuals) or systems advocacy, we hope to provide you with some helpful tips and information. We have also included some important information about educational advocacy and self advocacy, if your sibling is able/wishes to become involved in peer-driven advocacy.

I. ADVOCACY WITH- IN YOUR SIBLINGS AGENCY:

The first step in being an effective advocate for your sibling is to **build and maintain a relationship with his/her caregivers and program supervisors.** Staff are almost always well-meaning people, and they are engaged in demanding, yet low-paid work. Acknowledge what they do accomplish with your sibling. If something goes wrong, **think before you speak, strategize before you criticize.**

However well-meaning both parties are, differences between you and your sibling's caregivers are

more than likely to arise--be they around perceptions of your sibling's needs, the array and frequency of services available to him/her, or the adequacy of a particular staff member.

The following tips have been put together to help you problem solve by people who've "been there" -- siblings who've been overseeing the care of a brother or a sister with a handicap, and by AHRC's education advocate (see pg. 7 for phone number); note that many of these tips amount to good common sense:

◆ **Telephone the agency to request a meeting,** stating "up front" your question or problem. If you suspect the agency may be mistaken about specific information that you can double check, do so in

advance of your meeting.

◆ **Be sure you understand the facts of the situation and the available options.** Remember that additional options may open through discussion, especially if you **acknowledge that both parties have the same interest--the best outcome for your sibling.**

◆ **Call on other siblings or parents for advice.** You're not alone, and even if those you call are not familiar with the specific issues, they're likely to be of great emotional support to you. **Think about bringing the issue to a Sibling Support Meeting or contacting AHRC's Sibling Support or Advocacy Offices.** (See pages 6 & 7 for telephone numbers)

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◆ **Be persistent.** If you feel strongly about your position, “stand fast,” try to remain calm, and be polite yet firm. Other tips: have a supportive person accompany you to your meeting(s); take notes about what you hear, both in person and on the phone; try to limit the “wobble-room” of the agency by tying down acceptable options and time frames for proposed changes; and if you are writing letters, be sure they have a business-like look.

◆ **Speak to the supervisor of your sibling’s program if you feel you’re not making any headway with staff despite your best efforts,** and don’t downplay the seriousness of your sibling’s situation.

◆ **Use the agency’s “complaint hierarchy” or grievance procedure.** Agencies, by law, must provide clients and families with the titles of staff who hear complaints. If necessary, firmly but politely tell the supervisor that you would like to pursue your complaint to the next level, and ask for the name and phone number of the appropriate staff member.

And finally, while most complaints are solvable by sitting down with agency staff, be aware that in pursuing an issue, you are acting within a broad legal and societal framework. Other options available to you include the local New York State’s Developmental Disabilities Services Offices, which oversee the voluntary agencies; the New York State Commission on Quality of Care, which investigates complaints of agency abuse and neglect; the New York City Bar Association, which can provide you

with a list of attorneys experienced in solving disability-related issues; and the media, which can be enlisted to highlight a problem or resolve a consumer issue.

II. SYSTEMS ADVOCACY: WORKING FOR CHANGE AT LOCAL, STATE, AND FEDERAL GOVERNMENTAL LEVELS

Systems Advocacy is activity undertaken to change the governmental structures; the laws, budgets, policies and procedures that determine to a large extent how our siblings’ agencies operate. **This kind of advocacy may take a good deal of time and usually involves many people working together.** Such work can be very satisfying; you will meet like-minded people, and most importantly, you will be representing handicapped consumers and their families and helping determine policy directions. Group activity may take several forms: attending meetings and rallies, writing letters and/or making phone calls, visiting legislators, either locally or in Albany (or possibly in Washington), or speaking at public meetings and testifying at hearings.

Join or Start an Advocacy Group

You might consider becoming active in the advocacy group of your sibling’s service-providing agency, or in starting one, if the agency does not already have a group. When you become an AHRC member, for example, you are looked upon as an advocate and will receive “legislative alert”

mailings letting you know when the consumer’s voice needs to be heard (usually in Albany), the specific issue involved, advice on wording your letter, and a list of current New York City legislators and government officials.

In addition to advocating with your sibling’s agency, you may decide to work with other local or national advocacy groups. For example, each borough has a consumer/professional planning council which meets to assess local need and make recommendations both to the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) and to New York City’s Office of Mental Health, Mental Retardation, and Alcoholism Services.

Other organizations you may want to affiliate with include: United Cerebral Palsy, The Arc (The National Organization on Mental Retardation), The Autism Society of America, or one of the many other groups specifically organized around your sibling’s particular condition. Contact AHRC’s Advocacy or Sibling Services offices for additional leads.

Groups such as the AAMR (American Association on Mental Retardation) and TASH (The Association for the Severely Handicapped), are primarily professional societies, but have lower priced membership fees for the non-professional parent and/or sibling. Their mailings will keep you abreast of developments within the developmental disabilities field as well as issues they would like members to support or protest against.

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Guidelines for Effective Systems Advocacy

The Interagency Council (IAC), a consortium of New York City service-providing agencies, publishes an advocacy guide, compiled by Margaret Rausticala, TIPS FROM THE LOBBYIST'S LIT-TLE INSTRUCTION BOOK: The Parent Advocate Edition, which you and your group will find helpful. The following are drawn from it and from our Sibling Committee members' experiences:

General Advice for Advocacy Groups:

- ◆ Advocacy must be a continuing effort;
- ◆ Don't take on battles which you don't intend to see to conclusion;
- ◆ Limit the number of issues you intend to tackle, but hit them hard;
- ◆ Knock on the right door, take the time to identify who has the power and authority to best help with your issues;
- ◆ Build coalitions by contacting others who are already working on the issue or are likely to be affected by it;
- ◆ Create an ongoing "climate" of support for your issues by speaking to community groups and maintaining contacts with newspapers, cable TV stations, etc.

Advice for Visiting Legislators:

- ◆ Know your goal. Don't be inflexible, but know what is non-negotiable;
- ◆ Don't make outrageous, unrealistic demands as they will destroy your credibility;
- ◆ Listen carefully -- don't give a knee jerk reaction;
- ◆ Don't deviate from your group's agreed upon position, and don't ramble.

Writing or E-mailing Legislators (For specific Online Tips, see bottom right)

- ◆ In a short paragraph, state your position and ask for specific action--for example, that the legislator support your bill or speak to leadership in favor of it. Support your position with the rest of your letter.
- ◆ Explain how the measure or action will affect you, your family, and your community. Avoid making overly emotional or philosophical arguments.
- ◆ Ask for the legislator's support, don't demand it! Also, do not attack him/her or challenge the motives of your opposition. Remember that legislators respond to a variety of views; if they do not support your position on one issue or bill, they may support it on another.
- ◆ Respond promptly to a written answer: if there is agreement, express your thanks; if disagreement, write again indicating the likely adverse effects of your legislator's position.
- ◆ Be sure you write letters (or E-mail) to commend as well as to criticize or ask for something.

Writing/E-mailing Format:

The recommended address style for congressional legislators is:

The Honorable _____
United States Senate
Washington, DC 20515

or

The Honorable _____
United States House of Representatives
Washington, D.C. 20510

For state legislators, the similar format is:

The Honorable _____
New York State Senate
(Rm #) Legislative Office Bldg.
Albany, N.Y. 12247

or

The Honorable _____
New York State Assembly
(Rm #) Legislative Office Bldg.
Albany, N.Y. 12248

Begin your letter or E-mail with:

Dear Senator _____

or

Dear Representative _____

Systems Advocacy Online

Information from Web Sites

Gathering information from the World Wide Web (WWW) is an excellent, efficient way to stay in touch with your advocacy group's positions and to increase your knowledge so that you can be as effective as possible. If you don't have access to a computer and modem at home or at work, try the public library; almost all have computer stations where you can "surf the web" and many have facilities for you to E-mail legislators. The sites noted in the box on the following page are a few that might be helpful as you begin your online search for advocacy information:

E-Mailing Tips:

- ◆ Try to limit your E-mail to one typewritten page, two at most. Use proper net etiquette, such as avoidance of an all-upper-case letter, which connotes shouting.
- ◆ Don't *flame* (insult or disparage) or *spam* (inundate with E-

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mail, usually in an attempt to overload and crash the addressee's Internet system).

- ◆ Make sure your name, E-mail, and street addresses are enclosed. While many legislators receive E-mail, many can only respond by regular mail.
- ◆ Keep a copy of your E-mail;
- ◆ You may want to let your organization know you have contacted your legislator(s) so it can track how effective its own efforts have been with its membership and can lobby based on knowing whether the legislator has/has not already "heard" a great deal on the issue. Some organizations ask that you send your E-mail to them for forwarding so they can easily track member activity.

III. ADVOCACY FOR APPROPRIATE PUBLIC EDUCATION

The New York State Commission on Quality of Care puts out some excellent materials regarding special education law, the rights of children in the special education system, and the procedures parents or siblings should follow in order to obtain appropriate school services.

The Commission also sponsors free training sessions throughout the state to help educate families and to increase their abilities to better advocate for their handicapped children. Call the Advocacy Training Coordinator, collect if necessary, (phone number on pg. 7) or write to:

The Advocacy Training Coordinator
New York State Commission on Quality of Care,
99 Washington Avenue
Suite 1002
Albany, New York 12210-2895

for the materials, to find out about the training schedule or to arrange for private training.

AHRC's Coordinator of Advocacy Services (phone number on pg.7) advises or assists families/handicapped individuals who are having difficulty accessing or maintaining appropriate services, primarily in the area of special education, but assistance in other areas may also be available. Services include reviewing educational evaluations and/or securing additional ones; explaining the rights of handicapped children and adults; developing effective strategies to access needed services; and, if necessary, attending meetings and hearings with families.

- ◆ **AHRC:** <<http://www.ahrcnyc.org>>
Offers an extensive web site with many helpful links.
- ◆ **The Arc:** <<http://thearc.org/welcome>>
A National Organization on Mental Retardation. This is an excellent starting point for information-gathering. It is especially useful for legislative information. To obtain advocacy training materials: <<http://thearc.org/ga/trainmat.html>>. For E-mailing a member of Congress: <<http://thearc.org/ga/legtips.html>>
- ◆ **The Empowerment Zone:**
<<http://www.smart.net/~empower/>>.
- ◆ **HandsNet:** <<http://www.handsnet.org>>.
- ◆ **FedWorld:** <<http://www.fedworld.gov>>
Useful for locating the full text of almost any law, bill, or piece of legislation on the state and federal level as well as links to almost any government web site.
- ◆ **The National Association of Social Workers, NYS Chapter** <<http://www.naswnys.org/senlist.htm>>
This site not only provides legislators' E-mail addresses but also offers a good deal of information on legislative issues and advocacy tips.

This list is by no means all-inclusive. Remember to be creative in your search for Internet information. Using a "search engine" such as Yahoo! <<http://www.yahoo.com>> will help you focus on sites specific to your topic, enabling you to locate information more easily. Be flexible with your search terms; use phrases such as "disability advocacy," "online advocacy," and "disability law." You can also locate a list of search engines simply by using the search term "search engine."

Communicating through E-mail

(Electronic Mail): Use E-mail to quickly compose letters in order to contact your federal and state legislators, many of whom are accessible via E-mail. To locate their addresses, visit the following web sites:

- ◆ For US Senators and Congressmen:
<<http://www.visi.com/Juan/congress>>
- ◆ For New York State Legislators:
<<http://senate.state.ny.us>> or
<<http://assembly.state.ny.us>>

This site also contains a great deal of information on legislative issues and advocacy tips.

IV. SELF-ADVOCACY

A fairly new movement, self-advocacy encourages handicapped individuals to join together to make their voices heard at program, agency-wide, and governmental levels. One of the very moving and effective mottoes of the Self-Advocacy Association of New York State is "Nothing about us without us."

AHRC has had formal self-advocacy channels for its program participants since about 1990. You or your sibling can call the Residential Services Office for the name and number of the self-advocacy coordinator for each borough's residences. For day programs, each facility director can give you/your sibling information about self-advocacy in the workshop, day treatment, or other day programs.

Handicapped people not connected to AHRC who are interested in a self-advocacy group can call the Self-Advocacy Association of New York State. (See back page for phone number)

SCENARIOS FROM ADULT SIBLING GROUP SUPPORT

Our group has seen the following scenarios over and over; only the names and circumstances change. The group's suggestions are included.

SCENARIO #1

Dan's sister Erin, a woman with

moderate mental retardation has lived at home all her life and attends an AHRC day program. Recently, Dan and Erin's mother died, and to Dan's surprise, left him in charge. Now Dan is responsible for advocating for Erin and for ensuring not only that she is personally protected, but that she also has plenty of growth opportunities. First, Dan was encouraged to join AHRC so he could add his voice to those advocating for new residential developments. Since Dan must also take care of Erin's current needs he was encouraged to put Erin's name on residential placement waiting lists at AHRC as well as on other agencies' lists. He contacted the AHRC Guardianship Office and began the process of becoming Erin's guardian. Finally, the group urged him to contact the social worker at Erin's day program. Since Dan works long hours and can't always be home, he needed the social worker to help him arrange in-home respite care and after-program recreation. Dan also had questions about Erin's program. Erin has had some recent mental health problems--perhaps related to her mother's death or perhaps not--and sometimes her symptoms are worse during program hours. The sibling group encouraged Dan to take time off to visit Erin's program--to look around, meet the people who work with her and supervise the program, to ask questions and learn how the program works. Dan began to develop a list of resources--people he could call for help or ask questions of. Dan is trying to do what the group suggests: keep records of information on Erin and notes on any meetings or telephone calls he has. But he is scared and tired. Sometimes he

feels like there isn't much support or much of a safety net. The Sibling Group tells him that it is normal to feel overwhelmed, scared, angry, and frustrated, and reminds him he has to take care of himself too by making sure that both he and Erin get respite.

SCENARIO #2

Amy's sister Emily has severe mental retardation and lives out of state. Although Amy is Emily's guardian, and sees her frequently, she hired a nurse to be Emily's local advocate, especially to monitor her seizure condition.

When Amy last saw Emily, she had a large ugly lump on her arm. Neither the nurse-advocate nor Amy had been called. Staff explained that Emily had fallen and showed Amy the doctor's report. Amy believes there should have been further investigation: Was the fall seizure-related? Could a fellow resident with behavior problems have been involved? Emily is not one to protect herself, nor is she capable of explaining what happened. Why wasn't Amy or the nurse-advocate contacted? What to do?

Amy decided to travel to her sister's residence, making an appointment with the social worker for herself and the nurse-advocate. She explained her concerns, trying not to be nasty, but making it clear that the matter required further discussion. A team meeting was called to discuss the incident, but not much seemed to be known about it. A thorough examination was ordered for Emily, although the doctor did

not think the injury was seizure related. Amy then contacted the state's quality assurance program to ask for help and a review, if possible. She also contacted the state guardianship/ombudsmen office to get additional ideas. Amy and the nurse-advocate reviewed Emily's chart to make sure that the request that they both be contacted immediately if Amy is injured is well documented. Amy insisted that Emily be moved to a room that was farther away from an aggressive resident who also lived in the group home. Amy planned to increase her calls and visits to Emily so the staff knew she was watching, and she decided to pay the nurse-advocate to make additional visits. They would have to see what happened, and though worried, they felt that at least for now, their plans will leave Emily's care more closely monitored.

SCENARIO #3

Sandy's brothers Peter and Mark are young men with moderate mental retardation and mental health problems. They live in the one residence near Sandy's mother's house that can handle their disabilities appropriately. Recently, however, when the brothers started "acting out" in ways they hadn't for years, Sandy and her mother learned that one of the "adaptation" programs had been discontinued; it had become too expensive to run without government support.

Sandy and her mother obtained information from the residence and from state web sites regarding the circumstances surrounding the regulatory changes. They contacted the other families whose members had been beneficiaries of the

program, and set about to collect their stories about the impact of the program's cessation on their loved ones. Finally, they researched the closure effects on families whose siblings, sons, and daughters were enrolled in other nearby agencies.

Sandy and her mother then linked up with several other families to work out ways to get the program restored. They discovered that the real problem was that there wasn't much understanding or support for programs designed for this group, and that even if this program were restored, it would continue to be on a precarious financial footing. They decided on a two-pronged strategy: to convince the funding agency to change the regulation by writing letters followed up by personal meetings and then clearly documenting what they had learned. If that effort didn't work, they would write and visit legislators and the legislative oversight committee. But more importantly, they began working on a long-term strategy to help both the legislature and the funding agency to deepen their understanding of the special needs of people with mental retardation and mental health issues, the impact of not addressing these needs, and the benefits realized from supporting prevention programs.

Sandy and her mother knew it was possible that their efforts would not restore the program for Peter and Mark or for other families immediately, but if they worked to restore the program and to educate as many people as possible about the unique needs of the group, their initiative would perhaps make a lasting difference.

SOME IMPORTANT PHONE NUMBERS

AHRC Membership:

212-780-2500

Joining at \$10.00 per individual will turn you into an instant "systems" advocate! You'll add your voice to the thousands of family members, friends and professionals who are currently members--and you'll receive "Advocacy Alerts," as well as AHRC's helpful and interesting newsletter, The Chronicle.

AHRC Sibling Services:

212-780-2592 Group and individual counseling for adults and children, and advocacy information; problem-solving assistance is also available.

OTHER DEVELOPMENTAL DISABILITIES ORGANIZATIONS TO JOIN

American Association on Mental Retardation (AAMR):

202-387-1968 or 800-424-3688

The ARC:

817-261-6003 (Formerly the National Association for Retarded Citizens of the United States; a rather nominal membership fee will put you on the mailing list.)

Siblings for Significant Change:

212-420-0776, Founded by a sibling, this group serves adults whose siblings have a wide range of disabilities. It provides a support network, a speakers' bureau, and more.

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AHRC New York Sibling Committee

Chair:

Ruth Pickholz

Vice Chair: 1

Kathryn Edmundson

Conover Brown, Jack Gorelick, Marsha Heiman, Julie Hyman, Charles King, Victoria Liska, Randy Rosen, Nilsa Santiago, Jeanne Sdroulas, Lee Slominsky

Issue Editor:

Marsha Heiman

AHRC Staff Representatives:

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200 Park Avenue South
New York, NY 10003
(212) 780-2500

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The Association for the Severely Handicapped (TASH):
410-828-8274 A world-wide organization of advocates.

SOME DISABILITY-SPECIFIC ORGANIZATIONS TO JOIN

Autism Society of America, Manhattan Chapter:
212-628-0669

Epilepsy Foundation:
212-633-2930

National Association for the Dually Diagnosed (NADD):
516-273-1300 Addresses the mental health needs of people with mental retardation.

UCP (United Cerebral Palsy) of New York:
212-979-9700 (Manhattan, Bronx, Brooklyn, and Queens)

UCP, Queens:
718-380-3000

EDUCATIONAL ADVOCACY

(Assistance with School-Related Issues)

AHRC Advocacy Services Office:
212-780-2534
Advocates for Children (Birth-21):
718-624-8450

New York State Commission on Quality of Care, Advocacy Training Coordinator:
518-473-7378 (Call collect if necessary)

INFORMATION AND REFERRAL

Resources for Children (Birth-21) with Special Needs:
212-677-4650

Note: Available as of Fall, 1998 is Information and Advocacy, A Directory of Resources for New York City Children with Special Needs and Their Families, and as of February, Special Camp Guide 1999, Camps and Summer Programs for Children with Special Needs.

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 schedule and information, call Dr. Randy Martin (212) 780-2592.

Only \$10 Will Make You a Member of AHRC



SYSTEMS ADVOCACY HOW-TO PUBLICATION

Interagency Council (IAC):

212-645-6360. Organizational memberships only, but call to request THE LOBBYIST'S LITTLE INSTRUCTION BOOK: The Parent Advocate Edition for your group.

SELF ADVOCACY

The Self-Advocacy Association of New York State:

212-627-2104 or 518-382-1454



SIB-Sibling Information
Bulletin
AHRC-New York City
200 Park Avenue South
New York, NY 10003