

SIB

Sibling Information Bulletin

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AHRC New York City

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PLANNING FOR EMERGENCIES: Compiling and Organizing Important Information

History

Over the years, our AHRC Sibling Committee has published a series of bulletins containing information about a wide range of topics. The purpose of these bulletins is to share experiences and critical information to make it easier for you—siblings especially, but we hope parents and other guardians will find the information helpful as well—to obtain the assistance required for the “special needs” people in your lives. Topics covered grow out of real-life situations faced by committee members.

The subject of this SIB (Sibling Information Bulletin) is documentation or paperwork: preparing in advance the official documents and family information that you will almost certainly need in an emergency. To take one of the direst of emergencies as an example, you may be faced with the sudden death or incapacity of your sibling's primary caretaker, usually your parent. “Being there” for your sibling, coming to terms with your own loss, as well as being responsible for initiating or reestablishing the routines of your sibling's life may be over-whelming. Knowing where important documents and information about your family and your sibling are kept, and that this paperwork is both current and organized, will be of immense help to you in handling the emergency.

We urge you and your parents and other relevant individuals to take the time now to begin to compile your “emergency folder.” To assist you, you will find a Checklist on the following pages, organized by category, of the documents, information, and items that should be in your folder.* As in other bulletins, we continue to highlight the issues with short sibling-written narratives. We have also included an annotated list of helpful websites, and finally, some summary tips.

**Note that the entire list may not be relevant to your situation, but it is important to begin to think through what you do need and to gather the materials.*

A SITUATION DEALING WITH THE IMPORTANCE OF THESE DOCUMENTS

José, a man with moderate intellectual disabilities, has been living with his sister, María, and her family in the three months since their mother died. During her lunch hour one day, María is in a car accident and is rushed to the hospital. Jim, María's husband, is frantic; he doesn't know the name or phone number of José's day program, the bus company that transports him, or the name of his teacher or social worker. María's address book has the names of lots of doctors, but Jim doesn't know which treat María, their kids, or José. Jim is trying to take care of the house, the kids, and José, and to be reassuring to María, who was severely injured. Had María compiled a folder summarizing the important facts of her brother's life and his emergency contacts, Jim would have had a much easier time “managing” the emergency.

SUMMARY TIPS

- We urge you to take the time now to compile the fairly extensive documentation you will almost certainly need on behalf of your sibling in an emergency. Use our “Checklist” to help you with the range of items needed and their organization.
- Organize your emergency information using an accordion folder, a loose-leaf book or some other multi-part format.
- Use copies of official documents, noting in your folder the location of the originals. Be sure the Medicare, Medicaid, and Social Security cards are in a safe place; they should not be carried in a wallet.
- The non-documents, the personal information in the folder, may be typed or legibly-written. If your family's or sibling's information is hand-written, have someone else look at it to verify its legibility.
- Share the contents and location of the emergency folder with immediate family who may need access to it.
- Review contents of the folder periodically, especially the emergency contacts and medical information and medications. Dating the lists will reassure you that they are current.

A SITUATION FOR CHECKLIST # 1, IDENTIFICATION AND KEY DOCUMENTS

“Mr. G., Fred, cannot be paid for his work at day habilitation until we have a copy of his Social Security card,” said my brother’s “day hab” supervisor.

“But he has a number,” I said.

“We cannot pay him unless we have a copy of the card. It’s the rule.”

Fred’s card had disappeared from his file during his transition from Willowbrook to first one, then to another group home. While he could have obtained a replacement card by mail, Fred’s brother preferred to take the required birth certificate and Medicaid card to the Social Security office himself. With Fred along to share the experience, Mr. G. found that not only was the office not crowded in the morning, but Fred enjoyed the opportunity to sign the request form in the presence of the Social Security officer. For safekeeping, Fred’s brother asked that the new card be sent to his own home rather than to one of his brother’s programs, and he later sent copies to them. The card arrived within ten days.*

**See the Social Security Administration website, below, for obtaining or replacing a Social Security card.*

A SITUATION FOR CHECKLIST # 5, PERSONAL CHARACTERISTICS

Bobby Smith, a 61-year-old-man with mild to moderate intellectual disabilities, has been living with his 85-year-old mother who recently developed serious health problems that necessitated her placement in a nursing home. Because Mrs. Smith believed that Bobby would pre-decease her, she had never planned for him to live in a group residence. There are no other siblings, so Mrs. Smith has now asked a relative to be a “stand-by guardian.” Before the legal change was even effected though, Mrs. Smith and the “stand-by” made a list of important facts about Bobby: his likes and dislikes regarding food and clothing, his general routines and habits, favorite holidays and holiday rituals, behavioral issues and how they might be managed, etc. When an emergency residential placement was found for Bobby, staff was grateful to have the list to help them get to know him.

***AHRC or your local service-providing agency can help with referrals to attorneys and/or tips on filing for guardianship and subsequent changes*

(mark off information/documents as they are obtained)

1. Identification and Key Documents

- **Picture Identification:** Passport, Resident (Green) Card, or Department of Motor Vehicles Non-Driver's Identification Card (see DMV website, below), Naturalization Papers, etc. (Documents indicating immigration status are of prime importance since 9/11, and copies of them should be compiled for your emergency file.)
- Birth Certificate
- Social Security card
- Medicaid and/or Medicare card
- Individual Education Plan (IEP): most recent, or last school transcript (see NYC Department of Education's website, below). (These documents indicate that your sibling's disability is a developmental one originating before he/she reached age 21; other documents, especially psychosocial or medical evaluations should serve as well.)
- Other Personal Documents: Baptismal Certificate, Employee ID, etc.
- Miscellaneous "Access" cards that need a central location: Access-A-Ride Card, Metro Half-Fare Card, Library Card, etc.

2. Emergency Contacts

- **Family Members and Friends:** their names, telephone numbers, addresses, and indications of relationships or special connections

3. Medical Information

- **Medical-Care Providers** (primary care doctors as well as psychiatrists, psychologists, dentists, etc.): names, telephone numbers and addresses
- **Medications:** dosages, schedule for and manner of administration, discontinued medications and reasons for discontinuance (must be kept current!)
- **Medical alerts** (allergies or negative medication reactions)
- **Annual Physical Exam:** most current only
- **Psychosocial Evaluation:** most current only (these are performed every three years)
- **Special diets, dietary restrictions**

4. Programs, Activities/Routines

- **Day program Information:** agency name, address, phone number, and contact person/s name and direct phone number
- **Day program Transportation:** company name, contact person and phone, precise locations as well as times for bus pick-up and drop-off
- **Evening and Weekend Recreation and Respite Program Information:** agency names and phone numbers; contact peoples' names and phones
- **Basic Routines:** wake-up and bedtimes, meal and snack times, type(s) of snacks given, bath time, weekend departures from routine

5. Personal Characteristics

- **Likes and Dislikes** (e.g. food, clothing); daily rituals
 - **Favorite Holidays and Related Rituals**
 - **Difficult or Idiosyncratic behaviors** and tips on how to manage them
- Note: A "Letter of Intent," a "futures planning" document, available from AHRC, can be used as a guide in summarizing your sibling's personal characteristics and your family's wishes for his/her future.*

6. Parent/Guardian Information

- **Full Names, Dates, and Birthplaces** of parents and grandparents (often needed for hospital admissions and for death or funeral-related documents)

<ul style="list-style-type: none"> • Death Certificates of parents, non-disabled siblings over 18, or guardian (needed for guardianship and for guardianship succession, if not already on file) • Marriage Certificate of Parents (in some jurisdictions, needed for guardianship and for guardianship succession if not already on file) • Guardianship Papers (letters or decrees) • Medical and Life Insurance Policies: company names, phone numbers, policy numbers (this refers to your parents' policies in cases of their illness or death, in cases in which your sibling has medical coverage under your parents' policy or is a beneficiary to your parents' life insurance policies; and note that a special needs trust should be established for your disabled sibling if he/she is a life insurance beneficiary or if other funds have been set aside for him/her) • Family Tree with notations of death dates (for probate proceedings, and, in some jurisdictions, for guardianship) • Divorce Decree, separation document, alimony or child support agreement (occasionally for guardianship, and for your sibling's general support) • Family Attorney and Accountant: names, addresses, and phone numbers • Last Will and Testament: A copy, location of the original document, or the name, address, and phone number of the attorney who assisted with it (note, again, the recommendation, given in "Medical and Life Insurance, above, to establish a special needs trust on behalf of your disabled sibling) 	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>7. Financial Information and Related Items</p> <ul style="list-style-type: none"> • Location of the Passbook or Checkbook of your sibling or his/her representative payee (the person receiving SSI or other payments on behalf of your sibling): bank name and account number(s) • Password to relevant ATM's • Other relevant financial and banking information: annual SSI report; trust report for courts, etc. <p><i>(Note: You may want to discuss with your parents the addition of your name to their bank accounts or, alternatively, your obtaining power of attorney over their accounts; either will enable you to pay bills promptly in cases of their sudden incapacitation. A sample power of attorney form may be obtained over the internet.)</i></p>	<hr/> <hr/> <hr/>
<p>8. Residential Information and Related Items</p> <ul style="list-style-type: none"> • Parents' Lease and lease renewal documents or deed to residence • Parents' Co-op or condominium documents: names and phone numbers of Board members • Parents' Insurance Policies: property, liability, casualty, umbrella • Keys to Parents' residence and mailbox • Keys or combination to lock of residence where your sibling resides, if he/she is living independently or in supervised residence. 	<hr/> <hr/> <hr/> <hr/> <hr/>
<p>9. Service Agency Information</p> <ul style="list-style-type: none"> • Principal service-providing agency (AHRC, YAI, etc.): name, address and phone number of contact person • Service Coordinator: name, phone number, address (the service coordinator may be affiliated with another agency or be independent) 	<hr/> <hr/>
<p>10. Funeral/Burial Information*</p> <ul style="list-style-type: none"> • Name and phone number of cemetery; deed to plot or its location and the names of parties authorized to open it; deed to niche • Pre-need funeral/burial plan information • Funeral/burial wishes and family traditions • Clergy: name, denomination, phone number <p><i>Note: the Sibling Committee will be putting together a brochure devoted to funerals and burials</i></p>	<hr/> <hr/> <hr/> <hr/>

Important Web-Sites

New York City Department of Education: <http://schools.nyc.gov/default.aspx>

This site contains a great deal of information. If you are seeking a copy of your sibling's IEP (Individualized Educational Plan), enter those letters in the "Search" box to the left of the screen. Or, you may key this website to directly access the relevant information:

<http://docs.nycenet.edu/docushare/dsweb/Get/Document-44/A-820.pdf>. (pages 9 and 10)

NYS Department of Motor Vehicles: <http://www.nysdmv.com/>

Your sibling can obtain a photo ID through the Department of Motor Vehicles. Click on the section entitled "Driver Licenses, Learner Permits, Non-driver Photo ID Cards;" at the bottom of the list, click "more."

Medicaid: www.health.state.ny.us/health_care/medicaid

It is problematic at times to enter this website directly. Try this approach: Go to www.google.com and enter the phrase: "Medicaid in New York State". The first result will be Medicaid. Click on it and it will take you to Department of Health website for Medicaid. This site will answer many Medicaid questions and provide links to other information sites.

Metropolitan Transit Authority: www.mta.info

On the MTA site click on "NYC Transit" and, from there point to "Accessibility," which will take you to the link for The Reduced Fare Program. You will find not only information here, but you can download an application form as well. Scroll down on this page to a section called "Traveling on MTA Buses" and click on "paratransit section" (or type the words in the "search" box.). This section will provide information about the Access-A-Ride program.

OMRDD: www.omr.state.ny.us

It can be problematic at times to enter this website directly, so try the same approach as with Medicaid, above: Go to www.google.com and enter the phrase "OMRDD in New York State". There is much information for families, including a new, helpful, directory of dental clinics that accept Medicaid.

Social Security Administration: www.ssa.gov

This is a website with extensive, much-needed information. One of its best features is a "Frequently Asked Questions" section. The window is on the right side of your computer screen. You can choose a topic and click "go". A selection of questions on that topic will appear. Click on the question and an answer will appear. It also provides links to many other informative sites like Medicare and Medicaid.

Planning for the Future: www.nysfda.org

This is the website for New York State Funeral Directors Association. There is important information on prepaid funerals for persons on SSI and Medicaid.

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Layed out by Kate Mammolito, AHRC Department of Public Information

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The logo for AHRC New York City. It features the letters "AHRC" in a large, bold, serif font. Below "AHRC" is a solid black horizontal bar. Underneath the bar, the words "new york city" are written in a lowercase, serif font.