

- **Intermediate Care Facilities (ICFs)** provide the highest staff/resident ratio and include clinical therapists, and specialists to deal with behavioral or psychological interventions. Siblings with profound retardation or multiple disabilities as well as those who are more medically fragile, are best cared for in ICFs.

- **Supervised Community Residences (CRs)** have fewer clinical staff. Although CR residents (living in either a house or apartment) receive 24-hour supervision and regularly scheduled nursing support, they require less direct care. They function more independently and may need occasional assistance with budgeting, shopping, building relationships or conflict resolution situations. Many also require guidance in accessing community resources for their leisure and daily needs.

- **Supportive Community Apartments** are designed to serve a higher functioning group able to care for their own needs with some support from AHRC staff. Guidance is provided on, for example, planning trips, self advocacy, work related problems, banking, cooking or effectively using community resources. Special clinical staff may be called in from time to time for social, work related or medical interventions.

- **Individual Residential Alternatives (IRAs)** are a relatively new option. Due to a recent shift in state funding, all new residential funding is now for individual residential alternatives (IRAs) be it a free-standing supportive apartment for high functioning individuals requiring minimal staff support, or a more highly staffed residential environment serving individuals with profound retardation or those with multiple disabilities and special needs. The IRA format allows more flexibility, individualizing programs and tailoring them to a particular individual's specific

needs. Working together, AHRC staff, the family, and when possible, the disabled sibling, develop an individualized service plan.

**Residential Placement is a Process:**

- Apply Early
- Be Persistent
- Apply Everywhere
- Be Realistic

**Don't wait for a crisis to strike before applying.** This is the most common mistake. Families procrastinate for many reasons. Waiting until a parent ages, becomes ill or dies, or until the primary caretaker is faced with a major life-status change (for example, a job relocation or new marriage) creates stress that can be minimized by timely planning and early action.

**Applying now does not mean acceptance now.** Most people wait as many as ten years or *more*, before an appropriate residential placement can be found.

**Remember: there may be nothing available when you need it if your family doesn't apply now.**

**Use the time between application and actual placement effectively:** Make guardianship arrangements if you don't have any; check into the legal issues involved in properly setting up wills and protecting your sibling's benefits; visit several residential facilities and familiarize yourself, your sibling, and other family members with how things work. Change is never easy. The entire family, and especially your sibling need time to be comfortable with the idea. Generally, prior to admission, a future resident will have several opportunities to visit the residence, usually starting with an invitation to dinner. Overnight respite visits and camping are ways to acclimate your sibling to the experience of group living and being away from home (see pages 5-8).

**Case History #1:**

John is elated; after being under enormous pressure in a low paying job with an uncertain future, he has been offered--unexpectedly since he was a dark horse candidate--the position of his dreams, but in San Francisco! Since he wasn't expecting to get the job, he had put out of his mind the fact that his sister, June, for whom he is guardian, won't necessarily want or be able to move. John's other brother, Blane, will still live nearby, but hasn't ever been involved in the oversight of June's care, let alone visiting her. June is devoted to John, as he is to her but doesn't completely understand this situation. John wants and needs to take the position, for economic security, but doesn't want June to suffer for his choice. First John met with Blane and told him he will have to do more--Blane absolutely refused. He said he was being manipulated into caring when he didn't want to. This upset John sufficiently to talk with the social worker assigned to the group home that June lives in. He suggested that John might need to bring Blane into June's life (and vice versa) more slowly, and they started thinking about ways to do that.

John's more immediate problem was relinquishing his day to day oversight of June's care, especially since he is concerned about the quality of June's placement, but knows that a move would be both disruptive and maybe even impossible for fragile June. John lives so close to June now that he drops in on her 4 to 5 times a week. First, John planned out when he would come back to New York to see June. Then, because he was still concerned that no one would be watching over June enough of the time, he proposed that his neighbor, who had known June for a long time, look in on her once a week. One of John's friends says it won't be easy, but reminds him there is the mail and the telephone and his neighbor's "eyes and ears."

**Don't put all your eggs in one basket.** Gather information about the residential facilities offered by different organizations. **Apply everywhere.** What becomes available through one organization may not be as appropriate as the options opening up elsewhere. Remember perfection is hard to come by; be realistic. **Get on as many waiting lists as possible. Keep in touch with your contact on a regular basis.** This is a process that takes time and perseverance.

**Eligibility Requirements**

It's best to review your sibling's needs and options with an AHRC Residential Placement Counselor. **To get an AHRC application, call (212) 780-2512.** Applications are screened by directors at the borough level in which the potential candidate lives. An appropriate and successful placement for your sibling means finding a compatible group of people and the right site. Staff in a potential group home for your sibling may meet with your sister or brother, and family or guardians, in an effort to assess whether he/she would fit in successfully at that site.

**Key Questions to Consider:**

**How can I tell if it's the right place?** Nothing will be perfect in every respect. There will be some compromises you can make and others you may find unacceptable.

**Some things to think about:**

- **Safety:** Drive and walk around the neighborhood at different times to get a true sense of the neighborhood. Ask about the number of staff, their training and credentials; how activities are organized and supervised "in" and "outside" the facility?; Are there curfews, procedures for calling in late?; Is the facility designed for safety with such things as stair railings (especially important if your sibling is mobility impaired), window guards, shower mats, exits, fire extinguishers, good lighting?

As of fall 1996, about 2,500 people are on AHRC waiting lists for residential placement. The agency maintains a total of 349 residential beds including those in free-standing Respite programs. In the 34 AHRC locations in the New York City there are 15 free standing respite beds, 89 Supportive Apartment beds, 104 beds in IRAs, 31 in Supervised CRs, and 110 are ICF beds. These numbers are continually changing. However, shortages exist in all five boroughs with Queens having the largest number of people waitlisted. A moratorium on state funding for new beds, whether in residential, apartment or free-standing respite, began in fall of 1996. Further development is contingent on future state funding. Other factors inhibiting development are: real estate values; community dissention and stiffer state and local requirements.

- **Appropriateness:** Is the neighborhood and the house itself one in which your sibling will feel comfortable? Is the location accessible to work, day treatment, recreational and community resources?

- **Is the people factor right?** How many residents live in the house? Are there other residents at a similar level of functioning? What's the male/female ratio? Is the location accessible for family and for your brother/sister to visit their family home? Is your disabled sibling prepared to accept a roommate? Is the designated roommate compatible?

- **Who decides on furnishings and room decoration?** Can your sibling have his/her own TV or stereo? What about storage? Bathrooms?

- **Take a "litmus" test:** Talk to the House Manager and get a sense of the internal dynamics. How many staff members are on premises at all times? If there is no staff present because all residents are involved in activities outside the residence, is there a beeper or cellular phone system for reaching the staff? Are clinical support staff available on a regular basis (social workers, speech therapists, occupational therapists etc.)? How is health care handled? Who notifies the family/guardian about different issues? Ask to speak with the families of other candidates or of those already living at the residence.

- **What if I don't like the placement? What if we're not ready when a space opens up?** Agency policies may differ. Check on the rules at each agency to which you apply. At AHRC you are not obligated to accept a placement simply because it is offered. Your sibling's name will not go to the bottom of the list. Most AHRC placements are successful due to the care taken in the screening and preparation process. Nonetheless, some placements don't succeed and the client returns home. There is no stigma. AHRC continues to work with you on a better placement. Under certain circumstances, such as a family crisis, you may even decide to accept a less than ideal situation until an alternative comes up.

- **How do I know my sibling is getting what he/she needs?** Within 30 days of admission to a residential facility, it is required that the facility's interdisciplinary team prepare a detailed program plan defining goals and services needed by the individual to help him/her function as independently as possible in daily life, recreation, social and emotional areas. You will have an opportunity to review and suggest changes to this plan.

- **Can the family visit?** Absolutely. And your sibling can visit his/her family. Notify residence staff of your plans ahead of time since residents may have activities scheduled. AHRC's **Family Guide** to residential services lists family and resident rights you will want to know about.