

Getting past the psychological hurdles

Ambivalence: It's sometimes difficult for parents to take the first steps toward a residential placement, even in the case of aging parents who recognize the need. For his/her part, the disabled sibling also struggles about leaving the parents with whom he/she has developed strong bonds. It's often left to non-disabled siblings to initiate discussion and action. However, sometimes the non-disabled sibling's own uncertainty about what's best for their brother/sister, and the discomfort of broaching this sensitive subject with parents, can further delay timely action. You can find help by working with AHRC's counselors and by joining other siblings in AHRC's Sibling Support Group. **Contact: Dr. Randy Martin, Sibling Services Manager (212) 780-2592.** Should you be confronted with an emergency, the **AHRC Crisis Team** telephone number is listed at the end of this Bulletin.

Dollars and Cents: Who Pays for the Residence?

There are no costs to family members for essential services rendered in residential programs certified by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD).

Basic costs such as housing, medical, food, transportation etc. are currently covered by a combination of federal and state funds, the resident's wages and/or other income, and various entitlements (SSA, SSI, VA benefits and Medicaid, if the persons is eligible). The community residence assumes utility costs.

• **What if my sibling has earnings?** The amount contributed from these earnings (from wages or from other types of income) is based on a "sliding" scale. Rents vary and depend on how much he/she earns. The amount of rent is determined by a New York State formula which is based on the total amount of income that a participant "earns"; earned income such as wages, and unearned income such as social security, SSI or other sources such as special annuities. Some residents have no earned income. Rent is then based on just SSI. Others who work in competitive industry do not receive Social Security or SSI. Their rent is then based on earnings and, if any, other sources of unearned income. Should they lose their job, rent calculation are adjusted accordingly.

• **What if the resident can't meet the rent set for him/her?** People lose jobs and circumstances change. A person cannot be discharged from a residence if they lose their job or if their financial status changes.

• **How is spending money handled?** Each program provides a personal allowance to every resident. The amounts differ depending on the person's entitlement and the kind of program (e.g. ICF, CRs, IRA etc.). The personal allowance for each type of residence is set by New York State. **Personal allowances cannot be withheld. They cannot be used to operate the residence, or be applied to medical expenses, or any other purpose.** These allowances are for "personal" needs; anything from

clothing to recreation. Residence staff maintains a personal allowance ledger which may be reviewed by the OMRDD during its annual process of certifying the residence. OMRDD monitors a percentage of all the Supervised and Supportive Residences each year, reviewing their ledgers on a rotating basis. However, *all* Intermediate Care Facilities (ICFs) are checked on annually. A parent, sibling, or legal guardian is entitled to periodically review this ledger if he/she so requests.

Case History #2:

Madeline's sister, Joanna, has mental retardation and a secondary diagnosis of mental illness. Madeline's widowed mother, lives with Joanna, but recently Joanna has been wandering away from home. The last time she was picked up by the police, she was resistant, a situation that escalated. Joanna's mother had recently been offered a placement for Joanna, which wasn't perfect in her eyes. Now the family is under increased pressure to do something. Madeline and her mother have visited several times. The facility is not a perfect match--everyone admits that. Yet it seems that Joanna will be safe and that the staff--while having a high turnover rate--are caring and experienced with people with mental health issues as well as mental retardation. Madeline's mother wants to hold out for a better placement. Madeline wants to take this placement--Joanna has been on the waiting list for thirteen years--and hopes it works out. She has redoubled her efforts to search for other placements, but there aren't many other possibilities. Madeline thinks it will work with close family supervision, and is trying to convince her mother that there are no good choices in the situation--Joanna may be unsafe to herself and to others if this continues.

Types of Respite Services and Opportunities

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• **Free-standing Overnight Respite:** In order to assist families with this frequent and difficult caretaking situation, in 1985 AHRC created a free-standing respite program. Respite guests participate in appropriate, enjoyable activities. The agency presently provides **overnight and weekend** respite opportunities (totaling 7,000 out-of-home days) to approximately 500 New York City families annually. Children and adults can spend a total of 42 days per year for a maximum of 30 *consecutive* days. However, participants are encouraged to limit their stays to no more than 14 consecutive days to allow more families to take advantage of the respite sites located in all five boroughs. The homes, located in pleasant residential neighborhoods, are open 24 hours a day, seven days a week, 365 days a year.

After an initial screening, individuals of any functioning level may receive services **at minimum or no cost** at an AHRC site staffed by people with experience and good judgement, trained to cope with problems that may arise in the family's absence. Free-standing respite services can be incorporated into a person's Individualized Service Plan (ISP) under the HCBS Medicaid Waiver. *Note:* Respite services are provided to children and adults according to availability and appropriateness for the individual, on a first-come-first-serve basis. For information or to visit a respite house, **contact AHRC Respite Unit Manager.**

• **Weekend Hotel Respite:** Your sibling can spend a weekend at a hotel participating in recreational activities. This program is offered in each borough ten weekends a year (except Staten Island,

which offers eight weekend stays). Individuals must be 15 years of age or older, ambulatory, toilet trained, and have no major behavioral or medical problems. Weekends start at 7 PM, Friday and end 3 PM, Sunday. Each borough can accommodate five guests on each weekend. To set up a screening interview, **contact Recreation Supervisor (Hotel Respite).**

• **In-home Residential Habilitation Services:** Are provided to families on an ongoing basis in the home to assist them in meeting their caregiving responsibilities. Working with a service coordinator, families determine the actual services they need. For instance, an elderly mother may be assisted in bathing her son/daughter before a day program each morning; a child may be taken on weekend outings to give other family members time alone together; or a disabled individual may be assisted with developing skills that will make him/her more independent in daily living. The number of hours and frequency of service can vary, depending on availability of trained residential habilitation counselors and in-home client needs and eligibility. Currently, families are receiving from 4-24 hours a week of service.

Eligibility: Any family with a developmentally disabled member living at home who receives Medicaid may be eligible. There are no age restrictions. For children applying for this service, parental income is not considered. *Note:* Non-Medicaid eligible families should inquire about In-Home Behavior Management Training and In-Home Respite.

To access these services, contact **AHRC's Waiver Services Coordination Unit.** They will assign a Service Coordinator to your family who will develop a

service plan with you. The plan must be sent to and approved by New York State OMRDD. Upon approval, an in-home counselor will begin serving your family.

• **In-Home Respite:** AHRC offers In-Home Respite through a Family Support Services Contract. A family can be provided with a maximum of 10 hours per month of respite in their own home. There is no cost or Medicaid eligibility requirement. **For further information contact AHRC Home Care Services.**

• **Recreation/Day Respite Services:** A variety of recreation and leisure activities are provided through the Department of Camping and Recreation. Activities offered include, theater, photography, arts and crafts, sports and vacations. Activities can last two hours, a full day, or cover a two-week vacation. The program is designed to not only provide leisure time options, but also to help individuals gain new social skills, such as making new friends and arranging their own leisure time activities. *Eligibility:* Services are available to individuals with developmental disabilities in all five boroughs. Programs are geared to all ages and functioning levels from preschoolers to senior citizens.

There is an annual \$15 fee for this program. There may also be supplementary fees for individual activities, or for transportation. Program participants must fill out a recreation application and submit the results of a recent medical examination (including P.P.D. test) and proof of diagnosis of developmental disability (which can be a letter from your family doctor). There is an initial interview by AHRC staff before anyone can participate in activities. **For more information contact AHRC's Department of Camping and Recreation Services.**