

# Residential Care

## Home Away From Home

Sometimes a family feels they can no longer care for their daughter at home full-time. Parents may be getting older or have health problems that limit their ability to provide the quality care their daughter needs. The physical and emotional strain on the family may be too much to cope with, especially for the single parent. There may not be adequate support or respite care from the extended family or through the community. In some cases, the family feels that she will do better in a residential setting which can provide 24 hour care. Whatever the reason, making a decision to find an alternative living arrangement can be painful and difficult. Finding the right home is often hard, and sometimes impossible. The family must choose to either remain in their situation and feel drained, or place their daughter somewhere else and feel guilty. There is often no choice that is good for everyone. Parents may face criticism and judgment from others, and they will probably always feel some sadness.

## How do we find out of home placement?

It is probably best to contact your state Developmental Disabilities Administration (DDA). Today, children are not placed into state facilities (institutions). All of the agencies participate in a review of each case. If she is over 18, she automatically qualifies for Medicaid, which provides assistance in the home at crucial hours, foster care in a family especially trained to deal with her problems or a group home.

## When should we think about residential placement?

Some families keep their daughters at home for all of their lives. If sufficient resources allow for good support and respite services, this can work well. However, the life expectancy of women with RS is well into her 40's. When parents are in their 60's and 70's, it is difficult for them to maintain the level of physical care and attention she requires. They also must face the fact that their daughter may survive them. Parents should plan ahead for when they can no longer care for her at home.

## What options do we have for residential care for her?

Large institutional settings are no longer an option for people with disabilities. Small group homes are a least restrictive alternative, providing a home-like atmosphere in the community. Some families prefer to combine resources and benefits to provide her own house or apartment close by with full-time caregivers.

## How can we evaluate a residential setting?

Despite the best reviews by state case managers, you will never "trust" the quality of the residential setting without making a personal visit and speaking with the staff. There is no other way. And probably the bottom line will be an instinct, a gut feeling, that this is a good place. Certainly, ask the tough questions such as: Are your staff trained? Is the facility licensed? How often is it inspected by government agencies? Can I see your last report? Would it be okay for my family or my daughter's advocate to visit her and take her out occasionally? And, of course, the big questions; how much and what do we receive for this amount?

## How do we pay for residential care?

Whether she lives at home or away from home, those who care for her must be given adequate support and respite in order to meet her many needs. Caregivers need regular time off and some holidays without responsibility for the woman with RS. Caregivers should be provided with ample information about the woman with RS, and any problems, aids or adaptations that are necessary for her success. If she lives away from home, the caregiver should be contacted regularly by family members, who will always be her foremost guardians and advocates.

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