Caring for Someone with Developmental Disabilities

INTRODUCTION

All of us are aging. As an individual caring for your family member with an intellectual or developmental disability (I/DD) the very thought that you are aging can bring many a sleepless night asking questions such as: Who is going to be there to care for my family member when I'm no longer able? Where will my family member live? There are steps you can take now to help answer those questions. Where we live and how we are going to pay for where we live are two of the most crucial concerns in a person's life.

The first step toward being prepared is to work with an agency that provides services to individuals who have a disability. Another step you can take is to start talking with your local aging agency to learn about services for which you qualify. Your needs and wants are important too. The following information will give you an overview of how agencies can help you, what types of housing are available, and information on a financial mechanism that will allow you to leave resources for your family member with a disability.

WHAT KIND OF HELP CAN AGENCIES PROVIDE?

Agencies that provide services to people with intellectual or developmental disabilities offer a wide range of services.

Home care support

- Respite
- Housekeeping assistance
- Emotional supports

Physical barrier removal

- Addition of ramps
- Modifying doorways, bathrooms, kitchens
- Help finding affordable, safe, accessible housing

Transportation

- Assistance accessing public or non-profit senior and/or accessible vans or buses

Senior service and social event access

- Provide information on local senior services
- Offer support groups
- Work with theaters, performing arts centers , etc. to provide free or reduced entrance fees for performances
- Work with your Aging agencies to provide joint social events that both you and your family member can attend and provide staffing to give you a break

Counsel/advocate on financial aid & benefits

- Help navigate the social service system and resolve problems with agencies.
- Advocate for obtaining services for which you and/or your family member are eligible
- Assist in obtaining Medicaid
- Provide materials or workshops on financial planning (e.g. guardianship and trusts)
- Help with transition planning: stand-by

guardian, health-care proxy, and living wills

MEDICAL/HEALTH SERVICES ACCESS

- Help in obtaining appropriate medical services for both caregiver and care receiver
- Provide list of specialists for children and adults with disabilities
- Aid with transition planning and your future health needs, i.e. dementia care and frailty
- Provide support groups and counseling for emotional needs

HOUSING OPTIONS

You or your family member with a developmental disability may find your current living situation is no longer suitable, or that you need options for the future.While working with an agency keep the following principles in mind*:*

- Involve the person with a disability in the decision-making
- Consider options that maintain the family unit (e.g. supportive in-home assistance, merging households with other family members)
- Ask for as many housing alternatives as possible and research your community's options.

Home Ownership – gives the individual the most control over living arrangement. In-home services are provided through healthcare agency, DD provider agency, roommate, or community and family supports.

Reverse mortgages – A homeowner sells their home back to a bank. The bank pays the homeowner each month over a set number of years. At the end of the agreement the bank owns the house. This option gives homeowners a monthly income, while being able to stay in their own home.

Renting or Leasing – Most communities have market rent or subsidized apartments. Information can be obtained from state and local governments and housing agencies, housing advocacy organizations, friends, relatives, landlords & Realtors.

Home Sharing – Two or more unrelated persons sharing housing and expenses.

Supervised Apartments – DD agencies support individuals in their own or shared apartments. Apartment mate may or may not be an individual with DD.

Family Care or Foster Care – individual lives with another unrelated family. The family receives monetary support from state DD agency.

Group Homes – generally certified by government agency and operated by state or private provider.

FINANCIAL PLANNING

Planning for the future and ensuring that you and your family member are receiving all the benefits available can reduce stress now and prevent worry about the future. Below are things to consider.

Medicaid transfer penalties

- Transferring assets to a disabled child may disqualify the child for benefits.
- Consider using a Special or Supplemental Needs Trust. Make sure to consult an attorney that is an expert in this type of trust.

Obtaining Federal Benefits

- Enroll you and your family member with a disability in all federal (and local) benefit programs for which you are elgible.
- Parents must view their adult child with a disability as financially separate from themselves.
- It is the adult child's income, not parent's income, that is reflected on a Medicaid application.

For more information on aging caregivers caring for a family member with an intellectual or developmental disability please visit: http://www.rrtcadd.org .

Information provided in the fact sheet was adapted from materials submitted by the Center on Intellectual Disabilities, University of Albany, Albany, NY.

For more information about ACL

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