Questions to Ask Series

Care Options for Developmentally Disabled Seniors

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Introduction

Perhaps you have a loved one that is mentally disabled and now is a senior in need of increasing care. For some, your Developmentally Disabled Senior has already been in a system established for the Mentally Handicapped, and now you are finding out that because of increased care needs the current system is not enough. What does one do in this case especially considering Medicaid and Medicare changes as well as cut backs in the Developmentally Disabled industry?

Questions to Ask...

When selecting Care Options for Developmentally Disabled Seniors it is important to consider carefully what his or her current and future needs are that need to be addressed. Here are some questions to ask:

1. Does your senior do better in a family setting with care given in a Host Home setting? In most cases your senior would need an Adult Day Care program as well. Host home providers generally provide care through the evening hours.

2. Does the Adult Day Program offer a senior program that meets your senior’s individual needs such as wheel chair access, activities that are not overtaxing for a senior but nonetheless stimulating.

3. Does the Adult Day Program offer additional assistance with tube feeding, diaper changes and hygiene care?

4. Does the Adult Day Program offer transportation to and from the adult day program?

5. Would a group home be more suitable for your senior with up to six DD individuals in the home and a change over of staff throughout the day?

6. Does the Host Home or Group Home offer adequate respite to the caregivers?
7. Do you know who the respite caregivers are and what training they have to care for your senior?

8. Are you connected with a Community Center Board that has a Resource Coordinator, which you are comfortable working with, and has your senior’s best interests in view?

9. Are you an active Guardian and involved in most if not all decisions about your ward?

10. Does the Group Home and or Host Home offer Supported Living Services?

11. Does the group home provide trained and qualified professional staff?

12. Is a nursing home more suitable to your disabled seniors needs?

13. Is your senior receiving all the resources available to meet their individual needs?

14. Have you thought of seeking advice from an eldercare attorney or from the legal center?

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Common Definitions

Adult Day Care Programs
Adult day care programs are for seniors needing a place to stay during the day because they have dementia or physical limitations and cannot be left alone. These programs provide purpose and stimulation through planned activities.

Community Center Boards
The boards (CCB) are the Single Entry Point to provide intake and Resource Coordination (Case Management) services generally providing financial and home and community support. They may either contract services from numerous other service providers, or provide services themselves.

D.D. or DD
Common abbreviation for Developmental Disabilities.

Developmentally Disabled Seniors
People with developmental disabilities have significantly limited daily living skills in two or more areas, and their disability impairs their general intellectual functioning. This generally occurs before the person reaches the age of twenty-two. Many have symptoms caused by mental retardation or related conditions such as, autism, cerebral palsy Down syndrome, epilepsy, or other neurological conditions.

Group Home Care
Most group homes are in a residential setting, generally a house with four bedrooms or more. A Lead Counselor is responsible for overseeing the day-to-day operation of the home. A Program Manager who holds a degree in a related field and has extensive experience providing supports to individuals with developmental disabilities supervises the Lead Counselor. Each group home is staffed twenty-four hours per day based on the needs of the individuals that live in each home. Overnight staffing may be awake staff that works the evening shift or staff that live in the home and sleep depending on the needs of the individuals.

Guardianship
Guardianship is a court appointment, which gives a person or an organization responsibility and authority for making decisions on behalf of an adult who is unable to manage his/her own affairs and make his/her own decisions.

Host Home Care
Host Home settings are often best for individuals who desire to live in a family-like or smaller setting. Host Home Providers are independent contractors; however, their contract requirements stipulate conformity to regulatory guidelines defined by the Division for Developmental Disabilities and quality standards established by a governing Community Center Board. Compliance is ensured via weekly and monthly monitoring visits by (CCB) management, nursing and administrative staff.
All Developmentally Disabled individuals living in a (CCB) governed residential setting are provided Supported Living Services ranging from money management, personal care, household duties as well as emotional and behavioral support. They also receive opportunities for pursuing recreational and leisure activities within their communities and transportation to and from activities and appointments. Most individuals attend day programs, workshops and or paid jobs in the community. Each Host Home generally has a Registered Nurse who works with the host home providers ensuring each individual’s medical and dental needs are monitored and met.

**Nursing Home Options**

If a Host Home or Group Home cannot provide the around the clock medical care your senior requires, perhaps it is time to look at what nursing homes offer. They can often be the answer to your seniors needs for aging especially providing extensive medical care. Many of the DD providers have not planned for senior care and this may be the only option depending upon your senior’s needs. Note that nursing homes can vary as to secure environments if that is a need for your DD senior. Also some nursing homes do not accept DD individuals.

**Private Care**

Most Developmental agencies and nursing homes take Medicaid patients or other government supplemental pensions. There is also the option of private pay care for the Developmentally Disabled just like many assisted living communities offer. Remember though these types of private care facilities do not process Medicaid claims and only accept private pay. The advantage is that if your senior has a trust the can afford private pay these facilities offer devoted one on one care for the remainder of your seniors life.

**Provider Service Agencies**

An individual or any publicly or privately operated program, organization or business approved to provide services or supports for persons with developmental disabilities.

**Respite Care**

Respite care provides a period of relief for those giving constant care to an ill person.

**Supported living services**

Provides services and supports tailored to the needs of the individual living in his or her own home or family home.

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Useful Links

2-1-1 Get Answers, Get Connected
2-1-1 where available, connects people services
www.211.org

AbilityOne Program
The AbilityOne Program is a federal initiative to help people who are blind or have other severe disabilities find employment by working for nonprofit agencies (NPAs) that sell products and/or services to the U.S. government.
www.abilityone.org

Americans with Disabilities Act
Information & technical assistance American with Disabilities Act
www.ada.gov

Autism Society
Organization working to improve the lives of individuals affected by autism through public awareness and advocating for appropriate services.
www.autism-society.org

BenefitsCheckUp
The National Council of Aging created this website to help older adults to quickly identify programs that may improve the quality of their lives. You take 10 or 15 minutes to enter information about your financial situation into an online questionnaire.
www.benefitscheckup.org

CARF International
Commission on Accreditation of Rehabilitation Facilities (CARF) is an independent, nonprofit accreditor of health and human services for aging services, behavioral health, medical rehabilitation, vision rehabilitation and other service programs.
www.carf.org

Committee for Purchase From People Who Are Blind or Severely Disabled
Independent Federal agency that administers the AbilityOne Program. The AbilityOne Program's mission is to provide employment opportunities for people who are blind or have other severe disabilities in the manufacture and delivery of products and services to the federal government.
www.abilityone.gov

Disability gov
Resources and information on finding information and opportunities for the disabled.
www.disability.gov

Disability Resources on the Internet
Improve awareness, availability and accessibility of information
www.disabilityresources.org
Disabled American Veterans (DAV) – 877-426-2838
Resources and services for disabled veterans & their families’
www.dav.org

Easter Seals Disability Services
Providing services, education, outreach, and advocacy to people living with autism and disabilities so they can be active in their communities.
www.easterseals.com

Government Benefits - 800-333-4636
GovBenefits.gov is the official benefits website of the U.S. government, with information on over 1,000 benefit and assistance programs. The website is a partnership of Federal agencies with a shared vision - to provide improved, personalized access to government assistance programs.
www.govbenefits.gov

Medical Travel Inc.
Disability travel resources and information
www.medicaltravel.org

National Association for Downs Syndrome (NADS)
Serving individuals with Down syndrome and their families (primarily serving families in the Chicago metropolitan area).
www.nads.org

National Association of PACE®
Programs of All-inclusive Care for the Elderly (known as PACE®) is innovative because the program provides continuous care and services offering individuals eligible for nursing home care the option of continuing to live in the community.
www.npaonline.org

National Institute of Mental Health (NIMH)
NIMH promotes research and training to aid in the discovery of the brain and behavioral sciences to find the cause of mental disorders leading to prevention, recovery and cure.
www.nimh.nih.gov

RHA Health Services
RHA Howell has been helping people with disabilities and special needs, and their families, make choices to live more independently for more than 35 years.
www.rhahealthservices.org

SATH - Society for Accessible Travel & Hospitality
Raising awareness of the needs of disabled travelers in the United States and abroad.
www.sath.org
Schizophrenia - Open the Doors
Providing resources and information to deal with the myths and misunderstandings about schizophrenia and mental illness.
www.openthedoors.com

The Individuals with Disabilities Education Act (IDEA) - U.S Department of Education
The Individuals with Disabilities Education Act (IDEA) gives states some flexibility in determining which departments or agencies may best provide the various disability programs that serve individuals from infants to adults.
www.idea.ed.gov

Travel For DD Population
Since 1972, thousands of men and women with developmental and physical challenges from all over the world have achieved greater independence through the travel experiences provided by The Guided Tour, Inc.
www.guidedtour.com

United Cerebral Palsy (UCP)
Leading service provider and advocate for adults and children with disabilities, including cerebral palsy.
www.ucp.org

Wheelchair Getaways
Equipment rentals to meet the needs of wheelchair travel.
www.wheelchairgetaways.com

Wheelers Handicapped Accessible Van Rentals
Wheelchair accessible van rental
www.wheelersvanrentals.com

World Health Association
This website has a section on disabilities ranging from activity limitations to participation restrictions.
www.who.int

Other Resources

Find your Local Area Agency on Aging through Eldercare Locator
The Eldercare Locator a service of U.S. Administration on Aging helps can connect you to your local Area Agency on Aging. Call 1-800-677-1116, Monday through Friday, 9:00 a.m. to 8:00 p.m., Eastern Time.
www.eldercare.gov
Area Agencies on Aging – AoA
Administration on Aging is the Federal focal point and advocate agency for older persons and their concerns. AoA awards Older Americans Act funds for supportive home and community-based services to the State Units on Aging, located in every state and U.S. territory.
https://www.acl.gov/

Medicare.gov – Official U.S. Government Site for Medicare
Medicare wants to "help you help yourself" by using Medicare's information resources to answer your questions.
www.medicare.gov

Centers for Medicare and Medicaid Services - CMS
CMS administers Medicare and Medicaid health insurance programs. They have a through website and they support a TTY user phone system for the deaf and hard of hearing public.
www.cms.hhs.gov

Have Questions?
Contact SeniorsResourceGuide.com by email: SRGinfo@SeniorsResourceGuide.com or call us at 303-794-0799.

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NOTE: This E-Guide was created for general information purposes only. It is not an official resource. Although every effort has been made to ensure the accuracy, we do not guarantee that there are no errors or omissions. Also be sure to check references and corroborate information from multiple sources.

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