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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 a senior requiring increased care. For some, your Developmentally Disabled Senior may already be 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 do you do in this case especially considering in light of recent Medicaid and Medicare changes as well as cut backs in the Developmentally Disabled programs?

Questions to Ask...

When selecting **Care Options** for Developmentally Disabled Seniors, addressing current and future requirements is important.

Consider the following:

1. Does your senior do better in the family setting of a Host Home? Your senior will likely benefit from an Adult Day Care program as well. Host home providers generally provide care only during evening hours.
2. Does the Adult Day Program meet your senior's individual needs such as wheel chair access or activities that are not overtaxing 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 its site?
5. Would a group home be more suitable for your senior with up to six DD individuals in the home with staff rotation 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?
8. Are you and your senior acquainted with a Community Center Board Resource Coordinator with whom you are comfortable and who has your senior's best interests in view?
9. Are you an active Guardian and involved in most of the decisions concerning your ward?
10. Does the Group Home 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 senior's needs?
Perhaps they need more one-on-one medical care often not provided by Host and Group Homes. Most skilled nursing homes, however, are not prepared to accept DD individuals.
13. Is your senior receiving all the resources available to meet their individual needs?
14. Have you considered seeking advice of an eldercare attorney or legal center?

Notes: _____

Common Definitions

Adult Day Care Programs

These programs provide day supervision for seniors whose dementia or other criteria render them unable to be left unattended but, at the same time, 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 other related, neurological conditions such as, autism, cerebral palsy, Down syndrome or epilepsy.

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. The home may be staffed overnight by those staff awake from the evening shift or else ones that live in the home and sleep depending on the needs and care levels of the individuals.

Guardianship

Guardianship is a court appointment giving a person or an organization responsibility for, and authority to, make decisions on behalf of adults (or children) unable to manage their affairs and make 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 (CCB). 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 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 senior's aging needs especially regarding the provision of extensive medical care. Many DD providers do not plan for senior care and, depending on your senior's needs, this may be the your only remaining option. Note that nursing homes' secure environment arrangements vary and many nursing homes simply will not even 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 senior's 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 is a relief staff for those providing constant care to a family member or individual that they are a caregiver for.

Supported living services

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

An 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 quickly identify programs that may improve the quality of their lives. Prepare to spend 10 or 15 minutes supplying an online questionnaire with information concerning your financial situation.

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

Provides 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

Government Benefits - 800-333-4636

The official benefits website of the U.S. government, with information on benefit and assistance programs. Search for specific benefits, such as financial assistance, food, housing, utilities, Medicare/Medicaid and more. Visit the website and use the "quick search bar" to find services.

www.govbenefits.gov

Medical Travel Inc.

Disability travel resources and information

www.medicaltravel.org

Mental Health Net

This website promotes mental health, wellness education and advocacy with a wide variety of online resources.

www.mentalhelp.net

National Alliance for Mentally Ill (NAMI)

Information about programs and services that NAMI provides across the country for people whose lives have been affected by serious mental illness.

<http://www.nami.org>

National Association for Downs Syndrome (NADS)

Serving individuals with Down syndrome and their families (primarily serving families in the Chicago metropolitan area).

<http://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 Depressive and Manic Depressive Association

Resources and help for individuals, their families and friends for dealing with mood disorders such as depression and bipolar disorder.

www.ndmda.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

National Mental Health Association

Community-based network dedicated to helping individuals live mentally healthier lives.

www.nmha.org

National Senior Citizens Law Center - NSCLC

Advocates for low-income elderly and disabled Americans before the courts, Congress and Federal agencies to promote the independence and well-being of low-income elderly and disabled Americans

www.nsclc.org

NISH - Creating Employment Opportunities for People with Severe Disabilities

NISH is one of two national, nonprofit agencies designated by the Committee for Purchase From People Who Are Blind or Severely Disabled [a federal government agency]. Its purpose is to support nonprofit agencies (NPAs) participating in the AbilityOne Program which provides employment opportunities for people who are blind or have other significant disabilities by procuring federal contracts for goods and services.

www.nish.org

Oxygen Travel Inc

Oxygen Travel arranges for prescription oxygen for domestic, worldwide and extensive travel plans.

www.oxygentravel.com

RHA Howell

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.rhahowell.org

SAMHSA's National Mental Health Information Center

The Substance Abuse and Mental Health Services Administration's (SAMHSA) National Mental Health Information Center provides information about mental health via a toll-free telephone number (800-789-2647) and through their web site.

www.mentalhealth.samhsa.gov

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 Arc [ARC] Link Incorporated

Association for Retarded Citizens provides an understanding of how the Federal system provides services and supports for people with mental retardation and related disabilities

www.arclink.org

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

Wheeler's 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.

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.

www.aoa.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

National Association of State Units on Aging – NASUA

Association through which state agencies on aging promote social policy in the public and private sectors to meet the current and future needs of older persons, adults with disabilities, and their families and caregivers.

www.NASUA.org

Have Questions?

Visit www.SeniorsResourceGuide.com and our national and local Internet directories to find other resources for seniors. The website lists 76 topics in 6 categories.

Go to www.SeniorsResourceGuide.com/National

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

Websites: www.Seniors-E-Guide.com | www.SeniorsResourceGuide.com

Seniors-E-Guide.com.com

This e-publication is available at www.SeniorsE-Guide.com

Other e-Publications: *Selecting Assisted Living & Higher Levels of Care*
 Selecting Active Independent Living & Retirement Communities
 Selecting In-Home Care/Companions or Home Health Agency
 Resources for Low & Moderate Income Independent Seniors

Contributors and Referral Resources for the Seniors E-Guide:

SeniorsResourceGuide.com Staff – www.SeniorsResourceGuide.com

Joan Therese Seivert – Connections Unlimited, LLC – Serving Denver Area - www.JoanTherese.com

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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