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> No Brain Injury is Too Mild to Ignore, or Too Severe to Lose Hope

# Helping Your Family Member Live Independently

Brain Injury Alliance of New Jersey

Brain injury can cause persistent problems in the activities of daily living. Memory problems can make it difficult to pay bills on time, or prepare meals safely. Sometimes these deficits are obvious, and are addressed during the course of medical treatment and rehabilitation. Sometimes they escape the notice of the person with brain injury, doctors, family members, and friends, until years after the injury. These problems can negatively impact an individual's ability to live independently and may result in the need to move the family member to a residential program or nursing home.

There are a number of services which can increase independence for persons with brain injury. They can help maximize independence and quality of life for people with brain injury by helping with the activities of daily living, by providing needed medical care while caregivers are at work or school, or by assisting individuals in the community. Other agencies provide information and resources related to independent living. This article reviews services to help your family member live independently.

If you have questions about the services described in this article, or want to receive more information, contact a Community Resource Specialist of the Brain Injury Alliance of New Jersey at <u>info@bianj.org</u> or 800-669-4323.

# 1. What are the different types of independent living supports?

#### Home health care

Home health care plays a major role in helping persons with brain injury live in the least restrictive setting. These services include professional nursing, certified home health aides, rehabilitation, medical social services, home support services, and case management. Services are provided by licensed professionals, including nurses, therapists, and licensed nursing assistants, who follow a doctor's plan of care. Planning for home health care supports can begin as early as initial discharge planning within the hospital or rehabilitation setting. This is especially the case when complex medical needs are present, such as medication management or wound care. The discharge planning team should address these issues with the person with brain injury and their family, to review what in-home health services are needed, and what the plan of care will be.



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Home health care can also figure into the lives of persons who are already living in the community. Medical needs can change, so that these services are needed to help someone remain in a least restrictive setting. Also, a person with brain injury who transitions from living with their family to living independently may find it difficult to meet certain medical needs on their own, necessitating in-home health care assistance.

Home health care services can be funded by private insurance, Medicaid, and Medicare. Each plan has different rules regarding what home care services they cover. Be aware of any restrictions your insurance policy may place on these services, and the length of time for which they'll pay for services. If you need additional help in funding these services, you may be able to obtain it through one of the agencies listed in this article. No matter who funds these services, be sure to keep copies of the medical records prescribing this care, as the case manager will ask to review these records.

Another resource which can assist in providing home health care services is the Statewide Respite Care Program. This program is administered by the New Jersey Department of Health and Senior Services. Different nursing care agencies provide services within each county. The services available include home health aides and private duty nursing. Applicants must be a resident of New Jersey with a chronic physical or mental disability requiring supervision or assistance with basic daily needs from a caregiver, age 18 or older, meet income criteria, and have liquid resources of less than \$40,000 (\$60,000 for couples). Based on income, there may be a cost share. To learn about the program, call your Area on Aging Office at 877-222-3737, or visit the website: http://www.nj.gov/health/senior/respite.shtml.

There are several resources to help you find the agency that suits the needs of you or your family member. You can contact the Home Care Association of New Jersey at 609-275-6100. They have a Web directory sorted by county: <u>http://www.homecarenj.org/directory/memdir\_county.cfm</u>. You can also contact the Brain Injury Alliance's Community Resource Specialists, who can help you locate an appropriate home health care agency.

## Chore and companionship services

Chore and companionship services can provide assistance with non-medical activities of daily living, such as errands, grocery shopping, laundry, etc. They can also provide social and recreational supports, such as companions



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who can accompany individuals into the community for shopping, entertainment and socialization.

Some home health care agencies can provide chore and companionship services. The Home Care Association or the Brain Injury Alliance, can help you locate a service provider. Many of these services are not covered by insurance. Make sure you know your insurance coverage policy, and speak with your case manager before trying to find a service provider.

The Statewide Respite Care Program can provide non-medical services like companions, homemakers, and supervision. The program is oriented more towards the needs of the elderly and those with physical disabilities; it may not be appropriate for the social and recreational needs of those with brain injuries. You may want to call the program and inquire as to whether it would be appropriate based on your or your family member's needs.

Each county has a program called Personal Assistance Service Program (PASP). This program can provide up to 40 hours a week of personal assistant services. To be eligible, applicants must be a New Jersey resident, physically disabled, between 18 and 65 years old, living in the community, capable of directing and supervising their own services, and either employed, preparing for employment, in school, or actively volunteering in the community. For more information, you can contact the Division of Disability Services at 888-285-3036, or view the program's website: http://www.state.nj.us/humanservices/dds/projects/pasp/index.html.

#### Home and Community Based Rehabilitation Services

Some brain injury rehabilitation facilities offer home and community-based services. Home and community-based services are typically prescribed by a consulting doctor or neuropsychologist. The goal of community-based rehabilitation is to improve a person with brain injury's independence in their environment, according to a plan of care developed by the case manager and client in conjunction with the service provider. The need for home and community-based services may not be obvious until time has passed since discharge from a rehabilitation facility. A person with brain injury may encounter greater difficulties after moving out on their own, or moving in with a spouse. Medical needs and cognitive conditions can change, requiring greater levels of support to help the person stay home.



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As with all in-home service providers, make sure you are familiar with your insurance coverage policies, whether these services are covered, and for what length of time. Check with your insurance, and be ready to provide medical and psychological records documenting the need for these services.

Locating a rehabilitation program that provides in-home services can start with the rehabilitation professionals that you're already working with, such as a neuropsychologist, cognitive therapist or occupational therapist. Also, the Brain Injury Alliance of New Jersey has a list of home and communitycan help find a program that will provide services within your county.

# 2. What are some resources for coordinating in-home supports?

Once you realize that there is a need for in-home supports to maximize independence and the quality of life, how do you determine which supports are needed, and figure out a plan to help a person with brain injury have the most independence and comfort in their community? Several agencies, including non-profit organizations specializing in independent living for people with disabilities, and state agencies that serve these populations, can assist you with planning these services and supports.

## Centers for Independent Living

Every county has an Independent Living Center (ILC), a non-profit agency which responds to needs in the community and takes action to eliminate barriers to independent living. The ILC in your region can provide you with extensive supports and services, including information and referral, individual and systems advocacy, peer supports, and independent living skills instructions.

You can learn more about ILCs, and get the contact information for your local ILC, by calling the Statewide Independent Living Council at 609-581-4500 or visiting their website at: <u>www.njsilc.org</u>. You can also call the Brain Injury Alliance for the contact information of the ILC in your region.

## The Elizabeth Boggs Center for Developmental Disabilities

The Elizabeth Boggs Center for Developmental Disabilities is the University Center for Excellence in Developmental Disabilities Education, Research, and Service. They provide training and technical assistance on community supports, including self-directed supports, and they can help



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families and individuals with disabilities in developing plans of care that are personalized and relevant to independent living. For more information, visit their website: <a href="mailto:rwjms.umdnj.edu/departments\_institutes/boggscenter/">rwjms.umdnj.edu/departments\_institutes/boggscenter/</a>.

#### Case management and support coordination programs

If you already receive case management services, then you may want to discuss the need for these services with your case manager. They can help you create a plan of care, and choose appropriate supports and services.

If you do not receive case management services, and feel that support coordination is needed to create an appropriate plan of care and implement this plan, then you may want to contact an agency that provides these services and see if you are eligible. These agencies may include:

## The Brain Injury Alliance of New Jersey

The Family Support program serves New Jersey families who have a family member with a brain injury living at home or expected to return home in the near future. To be eligible for Family Support, the family must live in New Jersey and be eligible for services through the New Jersey Division of Developmental Disabilities (DDD). The injury must have occurred before age 22 and have resulted in significant functional limitations.

## The Division of Developmental Disabilities

DDD arranges and coordinates needed services to eligible state residents who have severe developmental disabilities, including brain injuries that occur before age 22. The services include: case management, guardianship, family support, residential services, day programs, home and community based services through the Self-Directed Services program, and supported employment.

## The Division of Vocational Rehabilitation

The New Jersey Division of Vocational Rehabilitation Services (DVRS) provides services that enable individuals with disabilities to find jobs or keep their existing jobs. Vocational rehabilitation counselors work with individuals to develop an Individualized Plan for Employment (IPE) that is goal oriented and based on the need for services that leads to employment. DVRS purchases services from private providers, like neuropsychological evaluations, vocational evaluation, job placement and job coaching. Financial need must be established for some services, such as rehabilitation services and job training programs.



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## The Traumatic Brain Injury Fund

The purpose of the Traumatic Brain Injury (TBI) Fund is to allow New Jersey residents who have survived a traumatic brain injury to obtain the services and supports they need to live in the community. The Fund purchases services and supports that foster independence and maximize quality of life. This Fund is used when insurance, personal resources and/or public programs are unavailable to meet the needs of the applicant.

### The Traumatic Brain Injury Medicaid Waiver

The Traumatic Brain Injury (TBI) Medicaid Waiver is for persons 22-65 with a brain injury, and provides case management, community residential services, therapies, behavioral programs, day programming, personal care assistant, transportation, environmental modifications, respite, supervision, chore services and companion services for individuals who qualify.

### County Boards of Social Service

County Boards of Social Services provide eligible county residents with financial, medical, and social services assistance. Assistance can be granted for emergency circumstances, as well as to meet ongoing needs.

## County Offices of Disability Services

County Offices for the Disabled serve as a clearinghouse for information about programs and services, and advocate for people with disabilities and provide technical assistance. They may be aware of other programs run by local non-profits to help individuals with disabilities live independently.

To learn more about these programs, contact a Community Resource Specialist at the Brain Injury Alliance. They can explain these programs and help you understand which ones may be appropriate to your needs. Living independently in the community is a right, not a privilege. If you feel that you, or your family member, need in-home supports to live safely and independently in the community, call the Brain Injury Alliance. We will do our best to support your efforts and to connect you with the services and supports needed to achieve these goals.

*This article was written by the Community Resource staff at the Brain Injury Alliance of New Jersey.* 

Additional information can be found at our website, <u>www.bianj.org</u>.