



**BRAIN INJURY
ASSOCIATION
OF NEW JERSEY**

825 Georges Road, Second Floor
North Brunswick, NJ 08902
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www.bianj.org

Helpline: 1-800-669-4323

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

Planning for the Future Starts Today

By Carolyn Rocchio

Ideally, planning for the future of a family member with a brain injury should begin the day the injury occurs; however, when the future is measured in minutes and days, thinking about months and years in the future is unrealistic. There are many decisions affecting care and medical treatment in the early days after the injury, and families, out of necessity, focus their depleted energy on the most pertinent issues to avoid becoming overwhelmed with so many new and unfamiliar responsibilities.

This is an excellent time to call upon another family member or friend whose offer to help may be best utilized gathering information to assist the family in solving problems they will encounter in the future. One of the first places to begin gathering information is the social services/case management department of the receiving hospital. Social services case managers can provide applications for government benefits and other social service assistance programs, information about community services to assist individuals in need and other helpful resources. It is also important to check with the financial office of the hospital about insurance benefits, HMO limits, projected length of stay and/or any other payers that may be called upon to meet the bills.

In order to make decisions for an individual 18 years of age or over, it may be necessary to seek legal advice about the need for power of attorney or guardianship. Parents can legally make decisions for children and adolescents and are privy to all information regarding the child's health and welfare up to the age of 18. Some facilities, banking institutions, insurance companies and the like, however, will exercise their legal right to deny access to information to persons other than the named individual once the individual becomes a legal adult at age 18.

Although many families caught up in the life and death struggle for survival after brain injury reject the notion of litigation until there is more substantive information about outcome and future needs of the individual, it is critical to gather police reports and preserve important information relative to the scene of the crash or circumstances surrounding the injury should legal action be considered at a later date. It is always important to get legal advice about insurance benefits, victims' rights funds and other federal, state and locally provided funding sources.

Some states have registries to which hospitals are required to report the incidence of brain injury. Some of the state brain injury associations have formal or informal affiliations with the state agency monitoring these registries, whereby they may provide the individual and family with immediate assistance in the form of literature and other services. Contact



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the Brain Injury Association's Family Helpline (800) 444-6443 to learn how to contact the association in your state.

Hopefully, your family member will recover to an independent status in which he/she may continue life as before or with minor residual deficits for which strategies are in place to ensure functional capabilities. Brain injuries affecting vital cognitive and behavioral control and/or motor areas of the brain, however, often persist and restrict independence necessitating long-term support systems. When this is the case families must be careful about making decisions without knowing how decisions can affect funding sources, such as Social Security benefits. The two programs administered by the Social Security Administration for individuals with disabilities are Supplemental Security Income (SSI), which is a needs-based program, and Social Security Disability Insurance (SSDI), for individuals who qualify by having worked a sufficient number of quarters in jobs for which deductions were contributed to the Federal Insurance Compensation Act (FICA).

Over the months and years following a brain injury, the situation changes periodically, individuals move in and out of rehabilitation facilities and the home, lawsuits are settled, insurance settlements are awarded and caregivers pass away, necessitating additional changes. Any change or move should be explored and the financial impact of that change noted before actually making a move that may prove financially devastating or result in loss of services.

Case study: John was injured at age 19 and had not worked enough quarters to be eligible for SSDI, therefore he was awarded SSI and Medicaid, a state provided medical assistance program. After leaving the acute care hospital and completing a rehabilitation program, John was transferred to an adult living facility using Medicaid funds with an additional state-provided subsidy to support some continuing therapeutic services. His divorced mother, the family breadwinner, was unable to bring him home because of her working schedule. She had an opportunity relocate to another state for a better job opportunity; however, she did not look into ways the move would affect her son's situation. Sadly, she and John arrived in a new state only to learn that his SSI transferred easily but Medicaid, a combination of state and federal funds, is subject to the state's right to establish its own reimbursement rate and schedule of services. John ended up in a nursing home with no therapies provided, gradually became a nuisance to the other patients and was moved back and forth between one inappropriate place and another.

Another important issue to remember is never to leave money in the form of an inheritance or gift to an individual on SSI without first understanding its impact. There are legal remedies for leaving money for use by an individual such as special needs trusts, which preserve financial resources



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to be used for special items such as a television set, a recreational trip and items other than room and board that would enhance quality of life for the individual.

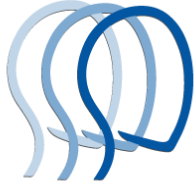
Any time there is litigation and compensation is recovered for the benefit of the individual with brain injury, the attorney should protect the assets by exercising legal options such as structured settlements, trusts and conservatorships. There are heartbreaking stories of individuals receiving large awards without adequate safety nets to protect assets. Within a short period of time the money is gone, with little or nothing to show for it. There is an additional risk of being taken advantage of by individuals whose understanding of the long-term reliance on settlement funds is driven by short-term gain. As parents age, there are new concerns about the time when the family support system no longer will be in place. If there is an expectation that other family members will assume caregiving responsibilities for the individual with brain injury, preparations need to begin well in advance of the time they will be needed. Regardless of who or where care will be provided, information about appropriate care requirements must be made available. Considering that direct inheritance can affect eligibility for government benefits, family caregivers should have written instructions outlining the way they want the individual to live, wills and/or trusts assigning successor guardians and/or trustees, disposition of assets and location of documents necessary for managing the future of the surviving family member.

Although it is difficult to project into the future and know the needs of your family member with brain injury, establishing short- and long-term goals is the best prescription for ensuring the future. The road to independence/interdependence is built from the foundation upward. Families utilizing informational resources and educational materials to increase their knowledge about brain injury and those involved in support groups, the Brain Injury Association and other self-help groups, seem to feel less stressed and better prepared for the task ahead.

“The most effective way to ensure the value of the future is to confront the present courageously and constructively.” (Rollo May)

Carolyn Rocchio is the parent of a son with a brain injury sustained in a 1982 automobile crash. She is the founder of the Brain Injury Association of Florida and a former Board member of the Brain Injury Association.

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*Additional information can be found at: Helpline: 1.800.444.6443
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