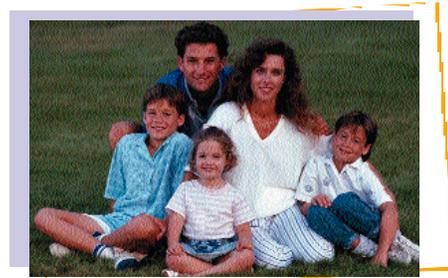


Relatively Speaking

Whose Responsibility Is It Anyway?

by Carolyn Rocchio



The most prevalent impairments subsequent to brain injury are severe cognitive deficits (Sundance & Cope, 1998) and the resulting neurobehavioral sequelae often are poorly understood by those outside the rehabilitation community. For the individual and family, the impact of brain injury is lifelong. Even when families are willing to be the primary support system for the individual with brain injury, they are, in most cases, inadequately prepared for the role.

Brain injury services have taken a step backwards during the reconfiguration of health care delivery brought about by managed care. The media is replete with examples of a scrooge-like system that turns out individuals “quicker and sicker.” The proliferation of brain injury services during the 1980s created a booming industry that generated millions of dollars. Along with this rush to provide more and better services, there was unquestionable abuse. For the most part, the appropriate regulatory bodies dealt with these abuses. The 1990s were called The Decade of the Brain, promising great strides in research and treatment. Instead, they became a decade in which managed care labeled physicians as “gatekeepers,” whose primary function was to orchestrate care their patients are able to access.

Rehabilitation benefits, once virtually unlimited except by policy caps, are so severely limited now that there is little time to accomplish more than some basic Activities of Daily Living (ADL) training (i.e, personal care, feeding, dressing, toileting) and motor restoration. Gone are the days of extended cognitive and behavioral rehabilitation with family services generously incorporated into the care plan. Neurobehavioral services, costly and labor intensive, were among the first to be denied as too expensive with little supportive data concerning its efficacy. All the more reason that families must now play a larger role because they have no options but to manage the best way they can.

The problems are there. Everyone is aware of them. But are there solutions? The answer is yes, but it takes more than a few family conferences and some literature. Brain injury does not respect age, ethnic origin, socioeconomic status or any other selective segment of the population. It is

society’s problem and it takes everyone delivering the same message to ensure that the life saved is a life worth living.

Providers, support group leaders, social services agencies and others serving individuals after brain injury ask, “where is the family when support is needed?” Simply stated, the family is one of the casualties of managed care, as reimbursement for family services is no longer a billable item. Once family members were acknowledged and encouraged in meaningful and productive ways by being included as members of the rehabilitation team. How can a family be expected to understand the many ways brain injury can impair an individual without witnessing it first hand in a setting with trained personnel demonstrating strategies for reducing the impairment? Hands-on experience is one of the few methods for families to acquire the skills they will need in the months or years to follow. Managing the cognitive and behavioral sequelae of brain injury is not just a matter of good parenting skills. It is an exhausting, often thankless job of understanding the family member’s strengths and weaknesses and how to provide the cueing, monitoring, structuring and other strategies necessary to maintain harmony and safety. Intensive interactive communication is required to accomplish that goal.

New technology that decreases secondary brain damage and allows for improved medical outcomes increases family optimism about recovery. At the same time, families are experiencing less awareness of and preparation for changes affecting cognition and behavior that may not surface until months after discharge. Decreased reimbursement for extended rehabilitation coupled with the busy lifestyle of families whose presence in the rehabilitation setting is not always welcomed or even looked on as a priority increases the possibility for greater dysfunction at a later date.

Good communication is as germane as the treatment one receives. It is particularly important that communication be established from the onset. When establishing this, it is important to keep in mind that immediately after the brain injury, people are usually the most upset and their ability to

listen to and understand often complex medical information is usually very poor (Blume, Carberry & Marion, 1993). Repeating information and requesting that the family keep a list of questions handy when meeting with clinicians enhances communication. Being more introspective, clinicians should remain sensitive to their own value system and philosophies regarding care, thereby improving their ability to communicate with families. In turn, this will maximize adjustment, understanding and involvement, and consequently facilitate the ongoing recovery process of the individual (Zasler, 1993). Balancing honesty while keeping hope alive is difficult but necessary.

No family readily understands how brain injury affects cognition, creating changes in functional capabilities. The neuropsychological assessment is key to the family's knowledge about 1) behavioral expectations following brain injury and 2) the degree of supervision and monitoring of the individual with brain injury (Rocchio, 1998), but often serves little purpose if the family and individual are not privy to the interpretation and recommendations. Every clinician has a role in emphasizing and reinforcing information using a multi-modality method. Information discussed in family conferences should be reinforced using audio or videotaping and supplemented with hard copies that can be reviewed by absent family members at a later time. The family's day-to-day presence on the rehabilitation unit helps them see the problems and learn how trained staff manages them. When the occupational therapist, in the course of evaluating perceptual skills finds significant problems, the individual and family should be shown how that deficit affects the ability to resume activities such as driving.

Families have a better understanding of cognitive deficits when they witness the struggle their family member may have trying to organize a task, perform simple math calculations or find the cafeteria. Successful generalization of skills acquired in rehabilitation is dependent upon the family's acquired knowledge of the problem, a realistic discharge plan, resources to call in crisis and their willingness to stick with it consistently.

During the rehabilitation process, issues almost never discussed with families include:

- Inappropriate behavior
- Sexuality
- Use of alcohol and other substances
- Importance of structured environments
- Consistency of family members in reinforcing strategies
- Planning for a stimulating and productive lifestyle after leaving the shelter of facility based care

All too often, families are blamed for not providing the necessary supports, but the reality is that they are often willing but inadequately prepared to take on the responsibility. Every step of the way, clinicians must be informing and

preparing families to become the support network. Discharge planning should specifically outline team recommendations to ensure successful community reentry. Additionally, the plan should include referral to the Brain Injury Association, support groups, Centers for Independent Living, Family Network on Disabilities, Vocational Rehabilitation and other agencies that provide recreation, socialization, legal and mental health services.

Along the recovery process, clinicians and, particularly, discharge planners plant the seeds for future growth and harmony by informing families of the need to sustain the supports beyond the initial stages of rehabilitation and community reentry. Withdrawing supports, once the individual no longer requires the assistance, should be a gradual process. Models for long-term support systems that have been proven successful are Mentoring (Blosser & DePompei, 1995), Circle of Friends and the "Whatever It Takes Model" (Willer, 1993).

Brain injury is a lifetime event and family caregivers must have many tools at their disposal to ensure that the life spared is a life of quality and not an additional burden to be borne and passed from one generation to the next. Effective communication at all levels of recovery and community living can reduce the incidence of re-injury, substance abuse, criminal activity, depression and disharmony.

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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