



BRAIN INJURY ASSOCIATION OF NEW JERSEY

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Helpline: 1-800-669-4323

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

Where do we go from Here?

By Carolyn Rocchio

Over the past few years I have written many articles about the experience of parenting a child with a brain injury, and for the most part the articles have been drawn from my personal experience. I frequently hear from readers with very similar experiences. I welcome their comments and suggestions about other topics of mutual concern.

There is a common thread that binds us all together -- "What will happen when I am gone?" It's not that we don't constantly think about this, because the truth is that it has been tormenting us from the first day we realized or were told our child would probably not achieve a level of functioning that would safely support independence. It is a thought that surfaces with each milestone in your life, whether it be a birthday, the anniversary of the date your child was injured or every time you have a bad day when you wonder if you can possibly make it through another day, much less another year. I sometimes feel that I must simply "live forever" in order to endure my son's well-being.

What We Know Now

Each year there are significant numbers of individuals whose injuries are so severe as to preclude them ever returning to fully functioning lives capable of independently managing their own lives. If we look at the statistics, we can determine that each and every year in this country one-and-a-half million people are newly-injured, and of these, 50,000-70,000 will be entering a lifetime of disability in an environment unaware of and basically incapable of meeting their long-term needs.

For the "pioneer" families, those of us who have been dealing with the devastation wrought by brain injury for many years, it may be too late for the latest technology to significantly impact upon the functional capabilities of our sons and daughters. However, progress made in early stabilization and treatment of persons with brain injury during this "Decade of the Brain" can improve outcome for those more recently injured. Last May at the meeting of the World Health Organization (WHO) in Spain, members approved universal guidelines for trauma care for brain injury. These guidelines are the culmination of many years of effort to improve trauma care, and the goal is for their worldwide adoption. These medically-proven guidelines should dramatically reduce severity of life long impairment.

There is still a wide disparity in access to and quality of services in many areas of trauma services and acute care services, but the greater disparity begins after medical stability is reached and rehabilitation services should



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begin. Inequality in funding sources impacts on who does and who does not receive rehabilitation.

The need for lifetime care varies considerably. Some individuals who are minimally responsive and/or severely physically impaired are generally unable to manage the most basic activities of daily living, and require full-time personal care, perhaps even continual nursing and medical care. Others may be very capable of managing personal care and many other meaningful activities with the help of an attendant/caregiver to assist with supervision, structuring and external cueing to ensure their maintenance and safety. The most difficult group for which to find suitable accommodations are those with severe cognitive, behavioral and/or substance abuse problems. Most currently live in homes with families disintegrating under the strain of trying to manage the situation and keep the family together and safe from harm. Others are housed in psychiatric facilities as a result of lack of appropriate and secure facilities with experienced staff to help them manage the cognitive/behavioral deficits that over their lifetime will be the most disabling.

This presents a dilemma in planning care to meet the needs of such a diverse population, and the biggest issue of all is how the cost of this care will be paid. It's with mixed emotions that I say that those whose support systems are funded through Medicaid may be better off in some selected states than those dependent on inadequate personal resources or other forms of benefits based on employment records, i.e., Social Security Disability.

Medicaid waivers, now in use in more than a dozen states, provide better options for those with Medicaid eligibility, and many of the waivers enable individuals to live more normal, community-based lives with built-in supports when these settings can be provided at costs less than nursing home care. This is a good first step in improving quality of life for many young people who were heretofore warehoused in nursing homes with older individuals as companions and little access to stimulating activities. However, overlooked altogether are those ineligible for Medicaid and whose limited personal resources will not provide access to services to increase their functional capabilities.

In an inconsistent manner, some states assist only those individuals with brain injury who meet the eligibility based on the Federal definition of Developmentally Disabled (onset of the injury under the age of 18 and IQ below 70). Various other states serve those whose injuries occur before age 18 without meeting the IQ threshold, which defines mental retardation.

Another area of concern is the insufficient numbers of caregivers with training in ways brain injury differs from other neurologically-impairing conditions. This applies not only to personnel staffing some facilities, but



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also to families poorly equipped to manage care in home settings. Until caregivers better understand the cognitive and behavioral changes and learn more effective methods of dealing with deficits resulting from injury to the brain, we'll still be where we are today. It is hoped that the new initiative of the Brain Injury Association to provide training through the implementation of the American Academy for the Certification of Brain Injury Specialists (AACBIS) program will make a difference in the quality of care provided by those certified caregivers for whom a discipline specific license is unavailable.

What Does the Future Hold?

There is reason to be hopeful, but patience is required. The 1996 passage of the Traumatic Brain Injury Act (TBI Act) was the first Federal acknowledgement of brain injury as a separate and unique disability, except for the 1990 inclusion of traumatic brain injury as a category to be served under the Individuals With Disabilities Education Act. The TBI Act is very dependent upon continued Congressional support to appropriate funding necessary to carry out the intent of the Act.

In this first year of the TBI Act (1997), the Department of Health and Human Services issued a request for proposals for state governments to prepare and submit plans for system changes that would create a seamless system of care to meet both the short- and long-term needs of persons with brain injury. The grants were announced within the past month, and states receiving funding began their proposed projects immediately. It remains to be seen what will develop from these grants in terms of long-term supports for which the federal or state governments may eventually appropriate funds, but these demonstration projects will undoubtedly validate what families have known for years: (1) the problem exists, (2) it will not go away despite increased prevention campaigns, and (3) extensive planning and creation of new funding streams for long-term community support systems and increased housing options are critical to solving the problem of where and how people with brain injuries live out their lives.

What Can We Do To Make A Difference?

The old adage, "The squeaking wheel gets the oil" is just as true today as always. Keep the pressure on your Congressional representatives to ensure they continue to view TBI as a priority. We can't let down our guard for even a minute. Make your family member's plight known to your State and Congressional representatives in a factual and non-confrontational manner. It is never appropriate to place blame or express anger at politicians for things they have or have not done, but those who represent you are interested in your problems, and your views and suggestions about ways your situation may be improved with their help.



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We are leaving the pioneer days behind us and moving into the millennium and "where do we go from here?" The road is uncertain and the answers illusive, but faith in the future will get us to our destination.

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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