

In the past few years, this Research and Training Center has interviewed hundreds of individuals about their lives after experiencing traumatic brain injuries. People were eligible to be part of this sample if they viewed themselves as someone who has “experienced a brain injury and has a disability.” A comparison group of individuals who view themselves as non-disabled was also interviewed. These samples include men and women from all regions of New York State — from rural areas, the cities and suburbs. People as young as 18 and as old as 65, of all races, income levels and life experiences participated in this research. In each issue of TBI Consumer Report, we will share some of the insights resulting from these interviews. Here we focus on PARENTING.

## What was the starting point for this research?

This study began in discussions we had with individuals with TBI who are parents. In talking about parenthood they mentioned both ‘clouds’ and ‘silver linings’ for people with TBI. The ‘clouds’ refer to concerns that TBI would get in the way of being a good parent. Fears that the children they have are suffering and that they, as parents, are not coping with the demands of parenting as well as they would like. The ‘silver linings’ they talked about included additional time many people had for spending with their children. Some parents, too, felt their children were stronger for what they had gone through. Hence, a mixed picture emerged, leading us to explore these views of post-TBI parenting in greater detail.

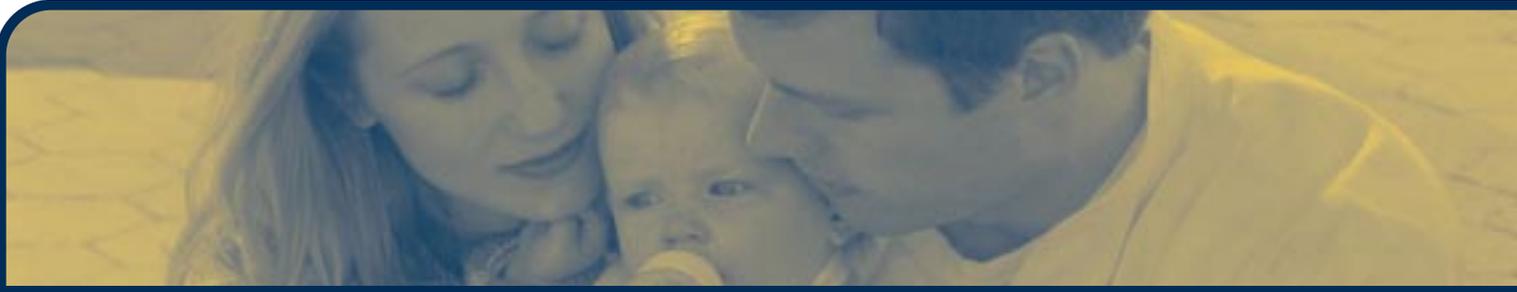
When we looked at research done by others we found studies showing that children of newly injured parents often have a rough time. They commonly experience feelings of depression and loss of attention due to the sudden, recent changes in their parent. However, no studies were available that took a look at children’s reactions to their parent with TBI over the long run. Nor did the research look at people with TBI many years after injury to see if their skills as parents were worse (or better) than those of non-injured parents. So, in our study, we asked, How do parents who are past the initial stages of injury meet the challenges of raising children — and how do their children fare?

We then contacted people (both with TBI and non-disabled) who had participated in a prior RTC study (see the box at left) who were parents of children between the ages of 7 and 18 living at home. We asked the person contacted, their spouse and one or more of their children to

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*“MY kids were born before my brain injury.  
Now I’m afraid I’m not a good enough parent.”*

*“Well, I’ve found that in some ways MY TBI has turned out to be useful. For example, I have to keep MYSELF so well organized that MY kids are learning this from me.”*



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participate. We interviewed 16 families in which a parent had had a TBI and 16 in which neither parent had a disability. Parents and children were interviewed separately. Each child was asked to rate each parent on 18 characteristics of parenting and then rated 13 aspects of their own life — for example, school, behavior, health. Each parent rated their own parenting skills and those of their spouse as well as their child's behavior. In this study, the average person with TBI was injured nine years before, enabling us to study what parenting is like and how children fare in families that have faced the challenges of a parent's brain injury for a relatively long time.

## What did we find?

When we compared **parents with TBI** to parents in families with no brain injury, we found **very few differences**. For *most* of the 18 skills evaluated, *no* differences were seen. For example, parents with TBI were similar to parents without a disability in the degree to which they encourage their children to think for themselves, in the degree to which they use anger or guilt to control their child's behavior and in how much stress they experience in running a household and in taking care of their children. In these and many other ways, parenting skills were very much alike.

Parents with TBI *did* rate themselves differently than similar parents without a disability in four parenting areas: They saw themselves as less accepting of their children, less able to express positive feelings toward their children, less encouraging of their children's skills and putting less pressure on their children to be orderly and conforming. Their spouses rated themselves as less loving and accepting than similar people whose spouses did not have a brain injury. Interestingly, the children, in their ratings of their parents' skills, did *not* agree with *any* of these perceptions held by their parents. Instead, the children in the families living with the consequences of brain injury saw *both* of their parents as being **less insistent on the child's following rules and standards** than in families with no brain injury.

In part, these differing perceptions between parents and children in households where TBI was a factor, may be due to another study finding. We found that parents after TBI were **more depressed** than parents without a disability; in fact, one in five parents with TBI were clinically depressed. In many families with a history of TBI, *one* or *both* parents were mildly depressed.

In looking at **the children's lives**, we found that in families where a parent had a TBI the child's behavior and daily life was viewed as similar to that of children in families without TBI (in the ratings given by parents *and* children). The only difference we found was that the children with a parent with TBI reported more **depression** than the other children in the study.



## What do these findings mean?

Because this is a study of families in which the parent with TBI was injured, on average, nine years prior, our results speak to the question of **what happens to parents with TBI and their children in the long run**. In the immediate period after injury, the results of other studies suggest that children often have a hard time of it. Similarly, the injured parent during the early period post TBI may not be as able to parent as he or she would like. But, our study suggests that with time, the parent can learn again effective parenting skills — working around or compensating for the cognitive, emotional and behavioral challenges he or she faces. The parents and the children we interviewed were in large part faring well — with very few ‘clouds’ to darken the picture.

This study does *not* suggest that *every* person with a TBI will be a good parent. But it does say that when we looked at parents with TBI, who had largely long-term injuries of varying severity, most have met the challenge of parenting to a degree similar to parents like them but without a brain injury.

The study suggests that **depression** is a problem and a challenge for many of the parents *and* children in families that are contending with TBI. In terms of enhancing the quality of daily life in these families, parents and children need to seek help in dealing with their feelings, which may include sadness, anger, hopelessness and/or helplessness. This may mean challenging the depression through increased involvement in community life, seeking the help of a mental health professional, reaching out to others (such as a minister or a local brain injury self-help group) or considering the use of medications or exercise to reduce depressive symptoms. These approaches have all been found effective in dealing with mood difficulties. Such actions are important for *all* members of the family, not just the individual with TBI, particularly since all too often the spouse and children are ‘forgotten’ or themselves assume that the person with the TBI is the only one whose needs merit attention.

The children in the families with parental TBI seem to be saying that *both* their parents are **more lax than other parents**. This suggests that parents and children each face a challenge. The parents may, when stressed by the realities of living with TBI, have less time and energy to pay attention to establishing structure, routines and expectations for their children. Their distraction with other important matters may communicate to the children that their parents do not care. For the kids, this mis-communication may translate into behavioral problems later in life. This is certainly an area of challenge that families need to look at carefully. In such families, parents need to exert more consistent discipline. Family meetings may help — at which guidelines and rules regarding children’s

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behavior are made explicit, including the consequences if rules are broken. Such rules might cover areas such as sharing household chores, doing homework, use of the telephone and TV, letting parents know of after-school plans, and the like. The parents' taking the time to communicate clear expectations about their children's behavior also communicates their caring, love and commitment to their children.

Finally, in terms of **limitations**, this research was done with a small sample of parents and children, at only one point in time. Because this limits our view of parents with TBI and their children, the need for future research is clear.

**Despite these limitations**, this study suggests three things to parents with TBI (including those who are considering becoming parents): First, you *can* do it. Others have — with the right supports (which every parent needs). Second, depression is a possible element of living with TBI of which the family members need to be aware. If depression exists in any family member, help of many kinds is available. Third, be sure that structure, expectations and rules for children are made — and are made explicit. The rules and consequences for breaking rules should be those that each family member can live with and that children know (through their parents' consistent actions) must be followed. Misperceptions that parents don't care enough to lay out their values and expectations can thus be avoided.

**To find out more:**

This study is being published in December 1998: Uysal, S., Hibbard, M.R., Robillard, D., Pappadopoulos, E., & Jaffe, M. (1998). The impact of parental traumatic brain injury on parenting and child behavior. *Journal of Head Trauma Rehabilitation*, **13** (6).

*"MY husband and I are both going to a support group now.  
It's helped us feel more upbeat about our lives and our kids."*

*"Yeah, my daughter was feeling down, too, after my injury.  
But our church group really reached out to her. It's been a big help."*

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