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ABSTRACT

This report is based on a qualitative research study which utilized a nominal group process to identify major life stressors for parents of children with traumatic brain injuries (TBI). It focuses first on effects of TBI on siblings and then on effective interventions. The first section uses quotes from participating parents to identify their personal needs, their need to understand their other children's pain, their desire for specific help, their concerns about explaining brain injury to brothers and sisters, questions about direct involvement by the siblings with the TBI child, and the need to balance their lives. The second section provides specific recommendations based on the research with parents and a literature review. These include the following: (1) give honest, simple, and concrete explanations and model involvement; (2) actively create opportunities for sisters and brothers to express themselves; (3) find informal (friends, neighbors and relatives) and formal (counselors) sources of support; (4) consider a sibling support group; and (5) work on balancing needs, interests, and time. The third section lists resources including two associations, three books, and two videotapes. (DB)

Sisters and Brothers, Brothers and Sisters in the Family

Affected by Traumatic Brain Injury

by Betty Pieper, B.S. Ed., R.N., C.

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Sisters and Brothers, Brothers and Sisters in the Family Affected by Traumatic Brain Injury

by Betty Pieper, B.S. Ed., R.N.,C.

This paper reports, in part, on the results of the qualitative component of our research especially relating to the parent consensus conference held in 1989 in which a nominal group process was used to determine major life stressors for parents and to recommend interventions they would find helpful.

The Principal Investigator for the grant is Susan Cox, Ph.D., the Director is Betty Pieper. The author of the report wishes to express appreciation to Dr. Cox for her support in this project and for her assistance in editing. The selection of parent material is a subjective process of necessity and the interpretations and opinions expressed are those of the author. Deep appreciation is also extended to Marilyn Lash, M.S.W., Director of Training at the Research and Training Center for Rehabilitation and Childhood Trauma, Tufts University School of Medicine. We look forward to future collaboration on both the research and the reporting of how families may nurture all their members, including the "other children" who experience the trauma of a family member's injury in different ways.

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Sisters and Brothers, Brothers and Sisters in the Family Affected by Traumatic Brain Injury

by Betty Pieper, R.N.,C.

SECTION 1: An Overview of the Problems, Needs and Solutions as Parents See Them

When an injury occurs in a family, it is natural that parents focus attention on the member who is injured. When the injured member is a child, there is a special urge to protect and to "be there" to ease the pain, the fear and the feelings of loneliness. If the injury is to the brain, consciousness itself may be lost and the parents want to be sure that the first person their child sees upon "awakening" will be them. They often believe, too, that their voices and presence may stir something in the child which will lighten the coma or increase his level of awareness and his recovery.

Who Takes Care of the People Who Care and Who Looks After the Other Children?

Parents often report keeping vigil at the child's bedside almost night and day, sometimes for days or weeks on end and to needing someone else to remind them of their own needs.

"I think some of us learned that from the hospital or some head injury association, some support person who got to us who said, 'You've got to take care of yourself,' or my husband and I would never have realized that we needed sleep or we had to eat, you know.' "

When the family member who is injured is a child and there are other children who need love, care and attention, the problems for parents can be staggering. Parents think about -- and worry about -- the other children as well. Even as they sit in the hallways outside of emergency rooms, they are torn between their concern for the injured child and the other children. Should they stay in one place so that they will not miss an opportunity to hear about the injured child's condition? Or, should they rush to a telephone booth in an attempt to reach a neighbor who will meet the school bus or see to it that their other child is not frightened by returning to a dark and empty house?

Their concerns range from how they will face their other children if the brother or sister dies, to how they will know "that our family at home is taken care of." When someone can and does meet these needs, parents are appreciative.

"I'm just lucky I had support -- I had family that said 'Okay. Johnny and Lilly are ours, we will worry about their day care. We will worry about their clothes being washed. ' We didn't deal with that. It was just -- and I had other people at school who were supportive enough and said, 'I will come and stay at the hospital while you go and spend time with your kids."

But there is not always "enough" support, partly because acute care and then rehabilitation may involve weeks, months or even years. Many programs are out of town and the logistics of dealing with everything and everyone may become enormous. Even if the parents are painfully aware that their other children are being "displaced," they are often at a loss of how to manage their lives any differently at any given point in time. At some point, some parents may have consciously put one or all of the other children "on hold" because they simply could not cope with any more. One mother put it this way.

"My older boy -- I mean, he was intact. In other words, alive, so I thought, 'Well, I will have to deal with him later, and months and months later, I dealt with the problem."

Parents may tell themselves that they are, in fact, serving the other children in the family and the family unit best by doing everything possible for the injured child. After all, they may reason, if the child regains physical and mental independence, the whole family will be better off in every way.

Typically, brothers and sisters see things more narrowly and from a shorter term perspective. Brothers and sisters may develop resentments and may have difficulty expressing such feelings. Guilt may increase their internal burdens. In some instances, a brother or sister will become deeply troubled, and, in our research, one father believes that his son may have lost his life largely because of the course of events triggered by their daughter's injury.

"I have three boys, and their little sister got hurt. Laurie was 15. My oldest boy was probably 22, and I have two boys that were born within the same year, Teddy and Tommy, Tommy which I lost. And, I don't know, we were just so busy with caring for Laurie. They were old enough to sort of watch out for themselves, but they were troubled.

I will say this, I wouldn't be surprised that my boy Tom -- it was very hard for him to cope with that. He would probably still be alive today if that little girl hadn't gotten hurt. It was very hard on them. I don't think we realized at the time because we were running back and forth -- we went 158 days back and forth, drove to ______." (He named a place 90 miles away.)

Most brothers and sisters, however, are resilient. It is important for parents to realize and for professionals to remind parents that these other children or "siblings" as they are called in social work literature, will likely develop many positive feelings for their sisters and brothers who have been injured. Probably the majority of siblings learn to express their feelings openly, to support their parents, to assist with the care of their injured brother or sister, to learn and to grow, to achieve and to fail in their own lives as typical children do.

Some view the experience privately; some have become advocates for the rights of all people with disabilities and have formed groups to support other brothers and sisters who are coping with the bitter sweet experience of having a child with special needs in the family. All are forever affected by their experience. This booklet is written in hopes of easing the way for all members of the family touched by traumatic brain injury.

"How Will We Know How Hurt Our Other Children Are?"

Parents who have looked back and wished they "had known" more about how their other children were feeling have asked each other, "How do you know, how do you find out what is really going on with them?" One woman talked about the way that she found out how one of her children was feeling.

"When I had gone home the first time after three and a half months they had in school what they called a journal where the kids would keep a diary that nobody would ever read in school, and Billy had all the pages stapled closed, and I opened it because I wanted to know -- he couldn't talk to anybody, and I wanted to know what he was feeling, and all he kept writing was, 'I wish it was me. It should have been me. It shouldn't have been my sister.' That's all he was feeling, and after we finally got home and got settled, I went to take them to counseling."

Except for the fact that Billy's class was involved in keeping a journal, it is unlikely that the mother quoted would have had a means to know what her son was feeling. Sometimes, children demonstrate symptoms so that their bodies express what their words do not.

"My daughter saw the accident. She had incredible sleeping problems. Crawling into bed with us. I mean, all kinds of things -- that we knew that she needed help."

What Would Help?

The parents in our research group addressed intervention strategies, both those known to be in effect somewhere and those which are only ideas, but which they think may help someone else. One mother suggested a checklist of symptoms and behaviors to look for in their other children.

"I know. There has to be some kind of a checklist to say, 'Is this sibling in trouble? Do you see this, this and this happening?' Not to the child who is injured, but to the surviving sibling. There are -- there has got to be some kind of -- he could be manifesting some kind of behaviors -- like Lilly couldn't sleep.

Another mother, who has training as a counselor herself, expressed positive feelings about the kind of help her son received from his school in helping him to keep in touch with what was happening to his brother each day.

"The child that was injured was nine and the older brother was 12. Our junior high school had a crisis intervention class, and they made a point of taking my older son out of the class every day at study hall and allowing him to call the emergency room so that he could find out what was happening at the hospital, and they dealt with him on a daily basis."

This mother goes on to explain what was missing, however, and a way in which she believes the group and the New York State Head Injury Association could help.

"The guidance counselor really couldn't help him (our older son) understand what a head injury was. He didn't have the information to prepare the 12 year old with what he could expect when his brother came home. They went out of their way to deal with my older boy, and the counselor kept him on his caseload for the whole year, and my older boy had a lot of problems in dealing with his brother, with the illness, with the trauma that he saw.

We thought that we were doing a really great thing by taking him down to the hospital to see his brother when he was in the Intensive Care Unit because we thought he looked great, and my 12 year old fell apart, and he really did need that crisis intervention counseling, but the point was that the counselor really didn't have the information, and neither did I, to explain to the 12 year old what he could expect when his brother came home."

In discussing what would have helped their other children, one mother noted that they tried to get counseling for their children, but the kind of help she had hoped for was not available.

"I wanted to get them counseling, and the first woman was Spanish, she barely spoke English. I said, 'Forget it. This is not the right thing.' -- The school knew about it -- his teachers and his counselor have tried to talk to him."

When parents see a need and believe that their child is benefiting from counseling, they value it. One of the mothers quoted above noted that they began counseling for Lilly when their son had been in the rehabilitation center for approximately three months, commenting, *"We had time for that."* A father thought that a good intervention might be group counseling or support groups.

"They should be where they can counsel with the families and meet like Al Anon dealing with the parents or brothers or sisters that are on alcohol, a support group. Sibling-to-sibling if there are, you know, other families with other children and let them talk it out."

Explaining Brain Injury to Sisters and Brothers

Parents could not always recall whether or not anyone tried to explain traumatic brain injury to their other children. Although many parents felt that such an explanation should be made to children, they were not sure who explained, when or what was said.

"I think my brother-in-law did -- He was a psychologist. We had that luxury of having a psychologist in the family who was watching my children. He was watching my children."

"Two-years ago. Johnny was eight and Lilly was seven when it happened. ------ There was nothing for them."

"They had no literature. Not in the hospital. The hospital social worker talked to them and said, 'Your sister's going to die.' Yeah. It was crazy and Billy couldn't deal with it. He was embarrassed to be seen with Nancy because she didn't move, she didn't talk, and she still doesn't. Now it's at the point where he will talk to me about it, and he will help her. He will carry her, he will, you know. I don't know what the answer is."

One mother, with a Master's degree in education, suggested that perhaps there was a need for "medical information down to your kids' level, I think, is what you are saying. Is there a need for a piece that would do that for you for different age levels that you could start with? I'm just brainstorming."

A father followed with, *"What about showing what brain damage is all about?"*

Another mother, quickly interjected, *"Not the awful aspects. Show it to them in a way they can accept it, because when they see their brother it's going to be a lot worse than this videotape, and at least that's preparing them that much for this, you know. A lot of hospitals don't let the kids in."*

Another father seemed to support the idea that children should know something about traumatic brain injury, but also seemed to reinforce the warning about the "awful aspects."

"Kids around the neighborhood were there when my son fell. They went to school, 'Oh, he is going to die.' My daughter was there. I think the kids as a whole in the school system should be taught something minor, not graphic."

A mother took up his theme regarding teaching all children, saying, *"They want to teach AIDS in the school program. Why not teach diabetes, head injury, everything else?"*

To which the father retorted, *"Because these kids -- my daughter freaked right out. She had no idea what was going on -- ."*

Seeing Is Believing -- But, Is It a Good Idea for Brothers and Sisters?

Not very long ago, our society said that young children should not be taken to wakes or funerals. It was felt that they would be emotionally damaged by seeing a loved one's body after death.

Quietly, some people began to say that children could be damaged by not being allowed to say goodbye in the same way their elders did. The controversy surrounding whether or not children should be allowed or even encouraged to see an injured brother or sister is not easy to sort out. Here is how some parents have described their experiences.

"Sam was four at the time, and Billy and Suzy were 10 and 12, and Amy was in the hospital also, and she insisted on seeing her sister. We couldn't keep her away after awhile, and we didn't want her to see Nancy because Nancy had what they call a hopping device, which is all metal brackets holding her pelvis together. We didn't want her (Amy) to see her, and she (Amy) insisted after awhile. We couldn't keep her away, and we had to explain to both the kids that Nancy was sleeping. Her eyes were closed. She was sleeping, and she was hurt. She hit her head and she was hurt. She hit her head, and she was hurt."

"We didn't even know what the appearance of head injury is about. How could we let my son know? He saw the accident happen and when he saw his brother in the ICU unit, you know ."

"My children were right in the intensive care. They saw Keith. They talked to Keith. Keith couldn't talk back to them, but they talked to him. They kissed him. I think we explained it to them at the hospital."

One mother worked in a rehabilitation setting dealing with traumatically brain injured youngsters and families. She expressed a belief in getting the other children involved early and directly.

" Get the kids as much involved in the direct care as possible. From all of the families that I have come in contact with the siblings that are the most involved with the injured child's care are the ones that care the most, and they are the best adjusted. The child is afraid to go into the room, and this has to start right away, Day One, because you can't have them in intensive care and then drag the kid in. Christ, you know, you are going to shock them."

How Can We Balance Our Lives? Who Will Help? And How Much?

Many of the parents we listened to in our research and day to day over the years are acutely aware of the needs of their other children. They often talk at length about the need for more time, about not feeling as though they have time to take a bath or tend to personal needs, let alone be fair to their other children. Parents also seem painfully aware of the temptation to use their other children to help in caregiving and the other household responsibilities which would otherwise be unmet. One mother spoke directly to the issue when she was asked for a major stressor in her life.

"It is a big one -- sibling equality. -- Making sure that Dirk gets his time, that Anthony gets his time, everybody gets their time, and not putting too much responsibility on the older kids, the more capable kids in taking care of him, though I trust kids with him more than I trust any stranger in the world. -- I need help to make all that balance."

There is evidence that parents do not necessarily stop with brothers and sisters, but, in fact, even look to the close friends of these brothers and sisters in order to help fill the critical needs of the injured child.

"When it comes to social relations we find that we have to go out and ask friends. 'Sam needs to have someone to play with. Could you come over for an hour?' I mean, even if you have to call up your daughter or your son's oldest friend and say, 'Will you come over for an hour and just say hello to my son? It would really make a difference.'"

SECTION 2: Some "Tried and True" Interventions

The following section is a synopsis of our research with parents and a review of the literature on parent stress and sibling issues.

Communications:

1. Give honest, simple, and concrete explanations and model involvement. In order to do this, you, the parents and you, the professional, may need to get some information before you can tell the children. There seems to be a clear need for some kind of material (printed, videotaped, etc.) which will assist children to understand what has happened and how it will affect the child and their family. A booklet which should prove helpful to parents (and professionals not familiar with TBI) is titled When Your Child is Seriously Injured in an Accident ---The Emotional Impact on Families. (See Resource List in Appendix.)

Descriptive Talk: One general rule is to give descriptions, not interpretations. In other words, instead of saying he is "peaceful" or "sleeping" or "can't hear," say, "His eyes are closed and he breathes very quietly. When I talk to him, he does not answer me." The parent or professional can validate the child who says, "He can't hear me," or, "He's sleeping," by saying, "It *does* look as if he is sleeping, but it's really different." To "He can't hear me," one might say thoughtfully, "No one knows for sure how it is. I like to talk to him anyway. It makes me feel better to tell him we love him."

Many brothers and sisters of children who have experienced coma seem to have anxiety about going to sleep and becoming like their injured sibling. Describing coma or a low level of consciousness as "sleep" also creates an expectation that the child will suddenly "wake up" and be the same as before.

Developmental Levels: It is also important to take into account the developmental level of the brother or sister. For example, if the child is under 6, his sense of time will be poorly developed and "coming home soon" may mean tomorrow, the "end of the week" might be confused with "the end of the day." Also, children at different age levels fear different "hurts." Very young children will be frightened of changes in the face of someone they are familiar with and a bit later they may relate mostly to physical pain and try to figure out where the "hurt" or "boo boo" is. They may worry about bodily mutilation and seek to discover some body part that is cut off or changed. Sometimes even a cast can be frightening because they do not know for sure that a limb is still underneath.

Sometimes the hospital will have a social worker, pediatric nurse, play room teachers, or family services practitioner who specializes in childhood development. You should ask if there is a person who can give you insight into what your children might be feeling and how to approach them.

Modeling Involvement and Confidence: Sometimes demonstrating by actions and words a quiet, confident approach to touching, loving and care giving can be instructive and also nurturing to the people who watch. Such an approach can be used to overcome a child's fear, reluctance, or embarrassment and help them reach out to their injured sibling. Descriptive self-talk about what one is doing is informative and comforting to the patient and to younger family members. A parent can say, "I always like to feel her feet to see if they are cold or warm or just right. What do you think?" A pediatric nurse may say, "Now I'm taking this soft cast off to clean the skin. You may watch. This leg looks good, but the skin is dry. We will put some cream on. You may help me by handing me the white bottle. I am very gentle because this leg needs to stay very quiet now. Would you like to help smooth the cream very gently? See how much softer that is? We have done good work."

2. **Actively create opportunities for sisters and brothers to express themselves.** Children may still believe in "magic thinking" for many years, that is, as Mr. Rogers says, that "scary, bad wishes can make things come true." This is complicated further by the spoken threats so common between children. In the case of traumatic injury, it may be that one or more of the other children not only saw the incident but may have contributed in some way to the resultant injury.

It is very important that children of all ages be given opportunities to express their feelings. Unfortunately young children who cannot verbalize their fears may exasperate their parents by regressing to bedwetting, clinging to their parents and screaming when they try to leave, and other behaviors which exasperate already harried parents. It is important to remember that these behaviors may be the only expression they can offer. Slightly older children can be observed in play or play can be initiated related to the child in the hospital or away from home either with dolls or by taking roles. Parents can switch roles, too, giving the child a chance to be the mommy or dad leaving for the hospital in order to gain some insight into how the child perceives the situation. Even young children can make pictures or even tape recordings for the injured child or the parents. Both of these approaches reinforce that the child is valued and part of what is going on; they also afford parents an opportunity to learn what the child is thinking and feeling.

Many children like to express themselves in songs or poems and this can be encouraged. Older children can be asked to make a scrap book or keep a journal about what is happening in their lives or about their feelings. Since journals and diaries are difficult in concept and even more difficult to commit to unless they are "required," other approaches can be tried such as "Could you draw me a picture of the accident?" or "Tell me about your picture." "Today you should write down 2 things you would like tell Jeremy that happened when he was gone," or, "Please write down 2 programs you and I can watch together this week."

It is often useful to use play or programs or stories about "someone else" to elicit talk from children. Often children themselves will make up a tale about a "friend" in order to put forth some of their ideas or feelings. Even teenagers may answer direct questions about how they feel about something by telling you what they think instead. Parents have to learn to listen carefully and without judgement and to hear beyond the words ("Your voice sounds angry. Is that how you are feeling about this?") They also need to become good at finding ways to know what their children are thinking and feeling so that they can decide how to help.

Emotional Supports: Finding people who can help.

Friends, neighbors, relatives and other informal sources of support: Parents come in all shapes and sizes. Some are very demanding, opinionated, and quick to advise, judge or commiserate. They can take a course in active listening, but they will not be very good at carrying through. This doesn't mean they are bad parents; they may be extremely loving parents who turn out highly motivated and caring children. But it may mean that someone else has to listen to their children at times -- just as they themselves advise, cajole, reprimand or challenge other people's children at times to the benefit of those children.

It is important to help your children find a friend for all seasons. You can help the child by doing a form of "fill in the blanks." Try to find out from your observations or from the child directly who they depend upon and why. ("When I am angry, the person I most like to be with is _______, when I feel discouraged, I like to talk to _______, when I'm scared, I like to know that_______ is nearby," etc.) If parents can overcome a feeling of resentment or jealousy, there are many people who can share in emotional support and growth for their children just as they themselves serve as surrogates to other people's children sometimes without ever knowing how important they have been in a child's development. Other times the help a child needs will be beyond what parents or an informal network can provide.

Counseling, Marital and Family Therapy, and Psychotherapy: Some sisters and brothers will need help from people who are trained in asking questions, listening to feelings, and assisting people in coping with their worlds. All counseling should be approached with the consumer asking questions before committing to professional intervention. The consumer should ask about the philosophical and treatment approaches of the practitioner, the projected time frame for a course of treatment, the costs, guidelines for participation and measures for determining progress or satisfaction. Usually professional references will be available, but patient/client references may be more difficult to obtain because of confidentiality issues. However, often your local head injury association support group or chapter will be able to give some input.

It should be clearly established who will be seen (the children and/or the parents) and under what circumstances (together or separately, etc.) Professionals should also be asked about their credentials such as whether or not they graduated from a regionally accredited college or university, what kind of experience they have had and whether or not they belong to professional organizations or have affiliations with academic institutions.

Counseling is usually used to describe a type of assistance which in which the helping professional can have various kinds and amounts of education and training but generally works with a person or group for a limited time, sometimes on a single problem, and does not go deeply into the past or the personality. Counseling generally tends to be descriptive and directive. That is, it deals with what is happening here and now and what can be done about it. The counselor may feel free to disclose some of his or her own perceptions and offer advice.

Counseling may be done with individuals or with groups. Groups are more cost-effective and can be powerful media for delivering support from others. However, there are many disadvantages. For example, some people have great difficulty sharing personal problems with anyone, let alone a group. Some people fear breaches of confidentiality, and sometimes one or two individuals may manipulate the process. Just as the reactions of others can be a source of support, challenges or disapproval from members of the group may be hurtful. The leader of the group should have very specific skills which are, in fact, not the same as the skills of the competent individual practitioner. Thus, group counseling should be approached with the same degree of fact-finding that the consumer uses with any other counseling service.

Marital and Family Therapy or Marriage and Family Therapy is a relatively new approach to counseling which combines some elements of individual and group counseling and requires specialized training. This type of therapy is usually short term, from 3-5 months, for example, and is often precipitated by a particular life stage, dilemma, or crisis. The particular problem which precipitated the call for counseling will be the focus. Family counseling focuses on relationships between people who consider themselves "family." Instead of focus on insight, exploration and growth or the individual, family therapy focuses on interactions between members of the family and the functioning of the family unit itself.

Although the therapy is family focused, each individual member of the family is assisted in identifying their own needs, hopes, and fears and is asked to work toward strategies to balance those with the needs, hopes and fears of the other members. Sometimes homework assignments or informal contracts and short term goals are set. The work of marital and family therapy is not to direct or decide for any individual, but to assist in decision-making through observations and exploration of options, including behavior change. The counselor seeks to support family members in their decisions, to help them to see their family as unique and to make use of the strengths of each family member and of the family unit. The approach practiced in marital and family therapy can be used to support families through separation and divorce as well as in marriage.

Psychotherapy is usually done by professionals who have extensive training in psychology and those who have become licensed may assess and give standardized diagnoses. Psychotherapy deals more with the past as an influence on the present personality, the patterns of a person's behaviors, and personal insight as motivation for more basic personality change. Psychotherapy is often done when someone is deeply troubled and/or deeply dissatisfied with their lives although anyone who wants to improve his or her functioning and life may enter psychotherapy. Likewise there are many approaches to psychotherapy. In general, the approach is usually less "directive" or advisory and relies upon a person deciding for himself what options will be explored and what changes will be made.

Sibling Support Groups:

The "sibling support" group for children does not use what we commonly think of as a self-help model. Whereas adults with mutual problems may get together and give each other support in a non-structured way, sibling support groups for children are best facilitated by a professional with counseling background and a more formal structure needs to be used than with adult self-help groups. According to Powell and Ogle (1885), "the counselor leading the group needs advanced helping skills if the group is to successfully meet its goals." Further, the leader should "model good communication skills and demonstrate respect and empathy for each group member."

Other suggestions are that:

- members should be oriented to the group process and the rules which will be used in communicating and should be assured of the kinds of confidentiality to be practiced.
- goals for the group should be discussed and the issues to be worked on understood
- groups are not necessarily on-going, but may meet for 5-10 sessions
- the age of the children in the group should be similar, usually within a 2-3 year range
- the educational and socioeconomic status of the children should be similar
- the meetings should be held in a comfortable setting which is free from distractions.

Some General Suggestions:

An injured child means an injured family. Unless the injury is minor and the recovery quick and complete, there will be many consequences for the family as set forth so poignantly in Section 1. How can all of these needs and interests possibly be balanced?

It may be enormously difficult, but it is important to remember that many families survive not only intact, but also feel that each member has grown individually and that they have developed a special quality as a family. The skills that can be learned in balancing interests in a family with special challenges can also prepare one for greater ease and success in the real world which requires constant trade-offs and give-and-take between people. Some of the strategies suggested for balancing needs, interests and time are listed below:

1. Let your other children know that they are loved. Tell them and show them. Spend time with each one individually in activities that they choose. Tell them that you want for them to have normalized lives, that you know they are separate and unique individuals.

2. Listen to your other children. Not just for their feelings, but for solutions to real problems. They will tell you when they think you are overly protective of their injured sibling, when they think they are not getting their fair share of time, attention or money. Sometimes you need to simply validate that they are feeling that way and you cannot change anything. But perhaps, something can be changed. State your dilemma and then ask what they suggest.

Children are good problem-solvers. Often children come up with solutions that you have overlooked entirely. (The solutions will often benefit them as well!) They may suggest, for example, that the family would have better access to sitters or to transportation if you moved to town. Or, that you would all have more time if you had a dishwasher or took turns cooking. Parents need to make final decisions to benefit the family as a whole, but children can and do give valuable input, and feel important when their suggestions are listened to or acted upon.

3. Tell your children how good it makes you feel when they interact in positive ways with each other, that family is very important to you. Show the value of family by doing things together.

4. Don't expect children to be saints and teach them to "fight fair" when they have disagreements. Be fair yourself in your expectations and disciplines. Make sure that your child who has been injured does not "use" his injury for special privileges or to make unreasonable demands on his or her brothers and sisters.
Acknowledging how a disability needs to be taken into account is different from lowering all standards or treating children in a discriminatory way on issues that do not relate to any disability. For example, you don't have to let the injured child get away with leaving his dirty clothes on the floor because he has a memory deficit.

5. Structure responsibilities for family members so that responsibilities fit their age, capabilities and interests as much as possible. For example, young children can bring in the mail, but older children could be taught to open and sort it as well as to write checks and keep simple household ledgers if they are interested. Tasks do not have to be limited to the traditional mow the lawn, take out the garage and babysit variety.

6. Limit the time required for responsibilities so that children have time for normalized activities such as birthday parties, studies, part time jobs, sports, and "hanging out" with friends. It is one thing for a child to help in taking care of their brother or sister, but it is not good when it gets to the point of these activities taking on the color of a role such as "other mother" or "the man of the house."

7. If one or more of your children have trouble interacting with the child who has suffered a traumatic head injury, tackle the problem. Sometimes siblings go from an intense involvement to extreme avoidance. For example, some children have tried to "teach" a certain skill and have utterly despaired: "What will become of him if he can't learn? He can't remember anything!" Other youngsters have been heard to vow an almost apostolic oath that they will take care of their beloved brother "for ever and ever and not let anything happen to him ever." Then, perhaps as frustration, embarrassment or simple reality sets in, the same child may go to the other extreme.

It is important to help children help at their own levels. If a child is intent on teaching or disciplining, for example, instead of discouraging him, find someone who will help him do it successfully. For example, children can learn the rudiments of behavior modification and could be instrumental in modeling and shaping appropriate behaviors in a sibling who has become agitated or disinhibited because of his injury.

If a child is embarrassed because of his brother or sister, it may be possible to educate close friends about the child's disability, to work with the school to bring the *Kids on the Block* puppets in for a performance and discussion, or to begin a campaign of education and sensitivity training relating to traumatic brain injury. Or, the children may be educated individually by having them share special times with the family where the strengths and special talents of the child with TBI are evident.

Chances are that if your "other children" are having trouble interacting and appreciating your child who has been injured, other people will, too. The resulting social isolation will hurt everyone so that it is important to tackle the problem as close to the source as possible, as soon as possible.

8. Talk to yourself -- and to trusted friends (or a counselor) -- about your own loss. Give yourself permission to be angry and confused. Parents of youngsters with TBI say that one of the most difficult things is that they grieve for the child who is lost to them. Yet, they still have the child -- a different child. Society has no way to recognize such a loss and no ritual from which to garner comfort and support. Parents feel entitled to their grief and yet guilty at the same time.

Sometimes they become over protective of their other children fearing that they might become victims of head injury, sometimes they feel that one or the other of their children should compensate for the lost child by achieving some special goal or even becoming involved in a pursuit in which the injured child excelled. Sometimes they do not want their other children to play the piano or enter competitive science fairs because that is "reserved" in their minds as belonging to the injured child and a painful reminder of lost abilities.

Most parents seem to be resilient and few seem to have any strange or pathological problems. Still, many report that they have benefitted from their self-imposed "mental house cleanings" where they look into the corners of their minds now and again just to reassure themselves.

SECTION 3: Some Resources

Associations:

Siblings for Significant Change
United Charities Building
105 East 22nd Street
N.Y., N.Y. 10010
Telephone: (212) 599-3360

Siblings for Significant Change is an organization of brothers and sisters who advocate for more normalized lives for their loved ones and for themselves. They educate the public, provide information to other brothers and sisters and assist in creating and sustaining support groups for siblings.

Siblings Information Network
A.J. Pappanikou Center
991 Main Street, Suite 3A
East Hartford, CT 06108
Telephone: (203) 282-7050

The Network began with the authors of Brothers and Sisters, listed below, at the University of Connecticut; the Network is part of a University Affiliated Program with members in many parts of the world. A quarterly Newsletter is available to individuals for $7.00 per year and to organizations for $15.00. Other resources include a bibliography of children's literature, a bibliography of journal articles and research on siblings, a bibliography of audiovisual materials and resources on how to start a sibling support group.

Books:

Lash, M. (1990) *When Your Child is Seriously Injured in an Accident --- The Emotional Impact on Families*. Boston: Tufts, Research and Training Center in Rehabilitation Medicine.

Although the booklet is written for parents, it is suitable for use with children as well because of its clear and concise style. Illustrations are by children. The booklet is 40 pages in length. For further information contact:

M. Lash/Rehabilitation Medicine
750 Washington Street, 75-R
Boston, MA 02111
Telephone: (617) 956-5036

Meyer, D., Vadasy, P., and Fewell, R. (1987) Living with a Brother or Sister with Special Needs.

Written especially for the brothers and sisters of children with disabilities, the book deals with such questions as: "What do I tell my friends about my sister?" and "Why do I feel angry (sad, embarrassed or jealous)?"

Powell, T.H. and Ogle, P.A. (1985) Brothers & Sisters; A Special Part of Exceptional Families, Baltimore: Paul H. Brookes Publishing.

This book is a treasure trove of everything from research on sibling relationships to reassurance. It is authentic because it relies on siblings to tell their own stories; it is useful because it blends sensitivity and common sense with cutting edge information and strategies for positive action.

Videotapes:

We are not familiar with any videotapes made especially for brothers and sisters of children who have been traumatically brain injured, but the two tapes listed here may be of interest to parents and professionals.

"The Other Children --- Brothers and Sisters of the Developmentally Disabled." (1-81) Four siblings talk about their feelings and relationships to their brothers and sisters who are retarded, autistic or have cerebral palsy. For further information:

Special Citizens Futures Unlimited, Inc.
United Charities Building
105 East 22nd Street
N.Y., N.Y. 10010

"What About Me? Brothers and Sisters of Children with Disabilities" is a videotape of interviews with brothers and sisters of various ages and their parents. A sibling support group is also featured. Children talk about their feelings ranging from frustration and depression to love and loyalty.

Some of the key issues addressed are:

- getting attention from parents
- having to assume more responsibility than other children from an early age
- wishing the brother or sister was not disabled
- dealing with the attitudes of friends and peers
- feeling left out, feeling different
- having less time to play
- feeling good about their brothers and sisters; thinking about the positive effects on their lives

The tape runs for 30 minutes and is for sale or loan. The list sale price is $250.00; the 2 week preview (loan) price is $35.00. For more information:

Educational Productions, Inc.
7412 SW Beaverton Hillsdale Highway, Suite 210
Portland, Oregon 97225
Telephone: (503) 292-9234/Toll-free 1-80‹-950-4949
FAX (503) 292-9246