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# Understanding and Implementing School-Family Interventions after Neuropsychological Impairment

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## Understanding and Implementing School-Family Interventions after Neuropsychological Impairment

Jane Close Conoley and Susan M. Sheridan

**C**HILDREN WHO HAVE suffered traumatic brain injury (TBI) or have neurological impairments due to disease, toxins, or genetic makeup present challenges that are best addressed by coordinated treatment and support activities among all their caregivers. Such systematic approaches to treatment, rehabilitation, teaching, and parenting are both complex to describe and difficult to create and maintain.

The goal of this chapter is to focus on one of the key systems that affects children's learning and behavioral adjustments: the interface between schools and families. Other *Handbook* authors have described specialized consultation to teachers needed to support their efficacy with children. This chapter offers information that psychologists can share with educators to inoculate educators to the unique stresses that families endure. Further, a particular approach to shared needs identification, goal setting, and problem solving is described so that educators and families can form a supportive team that enhances students' success. Finally, some of the other activities that school and families can share, such as advocacy and family education and counseling, are explored.

The etiology of a learner's neurological challenge is sometimes relevant to highlight given the different influences on recovery and on family functioning. Often, however, the educator is dealing with a child and family in need of help and support, wherein the etiology of the difficulty is unimportant. For this reason, we use the term "affected child" to refer to a child with neurological difficulties from any cause. If etiology does moderate intervention or outcomes, it is described specifically.

### THE AFFECTED CHILD: THE AFFECTED FAMILY SYSTEM

Educators faced with programming for special learning requirements may benefit from knowing some of the history of the affected child's difficulties, the level of fam-

ily organization around the difficulty, and the phase of acceptance or denial being experienced by the parents. The teacher is confronted with both a special needs child and a family system that has suffered the trauma of a child with disabilities.

Parents report an array of stresses when they first learn of their child's neurological difficulties. Family members display a sequence associated with their experiences. Both the difficulties and the sequence are instructive for care providers (Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; Leaf, 1993; Lezak, 1988; Livingston & Brooks, 1988; Livingston, Brooks, & Bond, 1985a, 1985b; Slater & Rubenstein, 1987). Although the educator cannot protect the parents from the stresses of raising a special needs child, understanding the parents' experience may assist the educator to be patient and supportive.

### RECOVERY MILESTONES

After serious injuries, parents report that their initial concern is the survival of their child (Rosenthal & Young, 1988). If the child is in a coma, parents focus almost exclusively on assisting the medical team in rousing the child. This process may be brief or may take many months.

When survival seems assured, parents turn their attention to acquiring information about the possible long-term consequences of the injury. Although many parents report high satisfaction with the acute care their child received, they often are dissatisfied with the vagueness of the information received from medical professionals about the effects of the injury. Understandably, parents want a specific listing of expected symptoms and a timetable for recovery. Medical professionals tend to share the entire range of possible injury effects, from the most serious to the most trivial, and they resist giving rigid recovery schedules (Bond, 1983; Panting & Mercy, 1972).

Parents describe serious concerns about the physical disabilities their child may suffer because of the injury, disease, or developmental disability. This concern abates as they either access information on how to accommodate the physical challenges or realize that their child shows few or no obvious impairments. In the process of raising a child with neurological problems, parents often say that the psychological, behavioral, and emotional challenges their child presents are far more disturbing than the physical limitations (Allen, Linn, Gutierrez, & Willer, 1994; Chadwick, 1985; Fletcher, Ewing-Cobbs, Milner, Levin, & Eisenberg, 1990; McGuire & Rothenberg, 1986).

Educators will encounter differences in parents' readiness to engage in home and school programming depending on the course of the neurological or neuropsychological problem. Parents who have had the child's lifetime to organize around their child's impairments may be immediately ready to engage, realistic about possible outcomes, and patient with small victories. On the other hand, depending on how the family is being served through other systems of care, the teacher may experience the brunt of a family's frustration with the affected child's slow progress or because of other family dynamics described later in the chapter.

In contrast, some pediatric recoveries from moderate and even serious injuries occur rather quickly at first. In these cases, parents are euphoric at the obvious improvements in their children's language, attention, and motor skills (Gardner, 1973; Romano, 1974). They may, in fact, deny the extent or permanence of likely disabilities (Martin,

1988). The optimism associated with early signs of rapid recovery may give way to sadness as recovery progress slows down significantly 10 to 12 months postinjury.

When the injury has been severe, parents begin to experience what some have called “partial death and “mobile mourning” (Rosenthal & Muir, 1983): Their child is alive but is not the child they knew before the injury. Although they thought they had grieved at the time of the accident, they tend to grieve again and again as their son or daughter misses usual developmental or social milestones. These may include starting school, playing sports, going to a prom, and graduating from high school. When the injury has been rather minor, leaving no physical sequelae, the children can suffer the pressures of being what might be termed “almosters” — they can *almost* learn like they used to, or they are *almost* as agile as they used to be (Jackson & Haverkamp, 1991).

Educators who are sensitive to the struggles being experienced by the students and families provide a safe haven of understanding for the family. Although interventions for change may be limited for some affected children, families benefit from valid information and from caregivers who are empathic to their despair and their hopes. Trusting relationships are the key to all therapeutic success. Understanding and empathy are cornerstones to trust.

#### SPECIAL FAMILY STRESSORS

A truism of family intervention is that all families have problems. What differentiates functional from dysfunctional families is not the number of challenges they face, but their skills in problem solving. Although there is likely much truth in this observation, there is little doubt that families dealing with a child’s difficulties are challenged by the number and duration of some of the stressors. Some of these are described next.

*Multiple Treatment Settings* Depending on the seriousness or recovery time of an injury or other impairment, parents may have to find alternative placements for their son or daughter. Short- and long-term residential care is not easily accessible to many families because of either its cost or its distance from their home (Jackson & Haverkamp, 1991). Such inaccessibility puts enormous stress on a family. Many families experience both challenges; that is, they must find ways to fund the rehabilitation process and travel long distances to be with their child during the first stages of rehabilitation (Brooks, 1991a). Even when a child can come home (or parents experiment with home placement), the young person’s special needs may force one parent to give up a job or demand a new network of support that includes medical care, supervision, and rehabilitation (Hall, Karzmark, Stevens, Englander, O’Hare, & Wright, 1994).

*Financial Stresses* The family’s problem-solving and coping resources are sometimes taxed because of the sheer number of tasks that demand attention (Bragg, Klockars, & Berninger, 1992). Financial strain due to medical costs associated with injury or disease is common (Hall et al., 1994). Financial demands include medical and often legal costs, as well as ongoing rehabilitation costs (e.g., assistive and augmentative devices, residential or partial hospitalization costs, and respite care) and costs related to modifying their home environment (e.g., ramps for wheelchairs). Although families may

be eligible for some insurance or state or federal (e.g., Social Security) financial assistance, accessing these funds can be difficult and time-consuming.

*Effects on Siblings* When the affected child is in an alternative treatment facility and educators are not directly involved with that child, the educator may still observe significant family difficulties. Other family members, especially siblings of the affected child, may vie for some of the attention lavished on the child with the disability (Dyson, Edgar, & Crnic, 1989; Simeonsson & Bailey, 1986). These attempts are tinged with guilt about their resentment toward their disabled sibling and with a sense of futility. Siblings report the perception that they will never do anything as significant as living with a neurological challenge.

In the case of TBI, Orsillo, McCaffrey, and Fisher (1993) suggest that siblings of individuals with severe head injuries experience psychological distress for up to 5 years postinjury. As siblings grow older, they also report realizing that the burden of care for their disabled brother or sister may fall on them. This is an anxiety-producing and sometimes anger-producing realization (Rivara et al., 1992). Although not a great deal is known about the relationship between psychopathology and having a sibling with a head injury, some studies have documented that siblings of children with other handicaps are at risk for developing behavioral problems (Breslau, 1982), anxiety (Breslau, 1983), social withdrawal (Lavigne & Ryan, 1979), feelings of guilt and anger (Chinitz, 1981), reduced self-esteem (Ferrari, 1984; Harvey & Greenway, 1984), and feelings of inferiority (Taylor, 1980). Generally speaking, siblings who are young, male, and close in age to the child with a disability experience the greatest difficulty.

It should be noted, however, that positive and constructive reactions to the presence of a disabled sibling are possible (Parke, 1986). Such resilient families, if identified by school personnel, may be a great support to other families dealing with similar challenges. Parent-to-parent networks have been shown to be excellent resources in many disability arenas.

*Managing Support Networks* Friends and extended family tend to be helpful in the first few months following a trauma or birth or diagnosis of a child with disabilities, but their attention and support drift as the long-term recovery and development processes continue. They may add stress to the nuclear family by offering irrelevant advice or even criticism to the family caretakers (Miller, 1993).

The family's skills in managing the systems that make up their world become critical. Parents often report disillusionment with medical and rehabilitation teams. Adversarial relationships are a constant threat to treatment progress. This adversarial stance, often developed during the medical and short-term rehabilitation stages of recovery following injuries, can set the stage for difficulties between families and schools (Martin, 1988). Parents may approach educators with a combative attitude, believing that only aggressive and demanding interactions will create service options for their child. Threats of legal action are common.

*Family Dysfunction* Many families report significant role strain or overload because of the special demands of parenting the affected child. These stresses can precipitate negative emotional reactions among family members, especially depression, blame, and anger (Zarski, DePompei, & Zook, 1988; Zarski, Hall, & DePompei, 1987).

Mothers and fathers frequently differ in the ways they react to their affected child. These differences (e.g., one parent is protective, concerned, and anxious, and the other parent is demanding and aloof) may be the source of considerable conflict among family members as the rehabilitation process progresses (Miller, 1993).

Family members may be separated for significant periods of time to assist in the rehabilitation process. This separation also contributes to role strain in remaining family members, as well as to potentially significant role changes. For example, older children may have to take on major responsibilities for child care and homemaking tasks. If the family has difficulty supporting each other during these stressful times, depression, substance abuse, and even divorce are possible outcomes (Hall et al., 1994).

The premorbid functioning of the family is a strong predictor of its members' success in coping with the affected child. Well-functioning families are especially helpful in promoting growth in their affected child's emotional and behavioral skills (Rivara et al., 1992; Rivara et al., 1993). The strong effect that families have on a learner's long-term outcomes is the reason coordinated home-school intervention is so critical. Educators and families working together are a powerful treatment for affected children.

#### ANALYSIS

Following their child's injury or the family's notification of their child's disability, family members can experience a dramatic swing of emotions, ranging from terror to euphoria, from dependency and bewilderment to anger, and through all levels of discouragement, depression, mourning, and, finally—ideally—reorganization. Family members move from being relieved the child will live to finding the child somewhat or very difficult. They can be blaming toward the child for not trying hard enough to learn or behave or recover from injury. Families can project their own feelings of lack of control on the child and other caregivers. Anger may be turned toward educators, therapists, or medical personnel if the child's condition fails to improve or worsens. Accepting that their child may not be the one they dreamed about before birth or experienced before an accident is very difficult. Family members may have to adjust their expectations from normalcy or full recovery to accepting that little or no change is likely. All parents have many dreams associated with their children. These must sometimes give way to new goals that involve a lifetime of dependency on the part of the affected child (Allen et al., 1994). The entire family system is traumatized by perceptions of the affected child's challenges.

#### CONJOINT FAMILY-SCHOOL CONSULTATION

Sheridan and her colleagues (e.g., Christenson & Sheridan, 2001; Sheridan & Kratochwill, 1992; Sheridan, Kratochwill, & Bergan, 1996; Welch & Sheridan, 1995) have described a powerful process through which school psychologists as well as other educators and families can join forces to assist children's positive adjustment to learning, behavioral, emotional, vocational, and social challenges. This process, conjoint family-school consultation, is described in some detail in the following paragraphs. It holds the best and best documented promise of forging a working alliance among ed-

ucators, school mental health providers, and parents (Guli, in press; Sheridan, Eagle, Cowan, & Mickelson, 2001).

A key element of family coping and involvement in a learner's recovery is a strong partnership between families and schools (Power, DuPaul, Shapiro, & Kazak, 2003). Reentry into the school setting following an injury or initial entry into a public school by an affected child may pose significant challenges for the child, the family, and the school. Families need the continued support of experts who can provide them with information, skills, and emotional support. Educators must rely on parents to continue educational programs in the home to improve their students' chances for optimal achievement. Frequent communication and shared decision making across home and school are critical for consistent and effective services. Cooperative consultative relationships between families and educators are essential to maximizing a child's education and treatment program (Sheridan & Cowan, 2004).

Establishing supportive, conjoint teams of parents, school psychologists or school neuropsychologists, and educators is a complex task. Education, medical, and rehabilitation experts often disappoint parents because the professionals simply lack the solutions the parents want so much. Professional teams often report that parental dissatisfaction with their work leads them to blame each other and weakens the team's functioning. These realities highlight the importance of working to develop constructive, trusting relationships among all caregivers, including family members, educators, and specialists (Christenson & Sheridan, 2001). Only in the presence of positive relationships are effective partnerships possible.

Well-informed school psychologists can be the critical link between families and school personnel. The families and the schools must engage in a mutual process that leads to reorganization around the affected child. An *empowerment* model is preferred over one that provides families with prescriptions for challenges the child may encounter on school entry or reentry (Dunst, Trivette, & Deal, 1994). In such a model, there is a focus on the strengths and problem-solving abilities of the family as a unit. Emphasis is placed on building support networks and engaging in collaborative decision making (Sheridan, Dowd, & Eagle, in press; Sheridan, Warnes, Brown, Schemm, & Cowan, 2004). Parents are considered an active and central component of educational programming for their child (including programs to meet their child's academic, social-emotional, behavioral, and vocational needs). For example, in a conjoint consultation model (Sheridan & Kratochwill, 1992; Sheridan et al., 1996), parents and school personnel share equally in the identification and prioritization of concerns to be addressed through individualized intervention. Parents, teachers, and school specialists work together to develop and implement a strategy or set of strategies to deal with the most pressing issues facing the child. Further, they continue with this dialogue as interventions are implemented and monitor the need for modifications to ensure the best possible treatment regimen for their child.

In situations that involve collaborative problem solving and decision making for a child affected with head injury, expertise related to medical concerns is necessary for coordinated care. Specialists from other disciplines (e.g., pediatrics, neurology, occupational therapy, physical therapy, speech-language therapy) are often important members of the conjoint team (Power et al., 2003; Sheridan, Warnes, Ellis, et al., 2004), and collaboration among relevant parties is important in the overall care of and plan-

ning for the learner (Drotar, Palermo, & Barry, 2004). The school psychologist or neuropsychologist can serve an instrumental, proactive role in maintaining contact with and inviting cooperation from these specialists (Shapiro & Manz, 2004).

A structured approach to collaboration is useful to ensure comprehensive and effective services. Four stages characterize conjoint family-school consultation, with three of the four stages involving structured interviews wherein the child's parents, the teacher, the school psychologist, and other relevant individuals (e.g., specialists) come together to address prominent concerns.

#### PROBLEM/NEEDS IDENTIFICATION

In the first stage of consultation, problem or needs identification, participants identify specific academic, behavioral, or social-emotional issues to be addressed. In the problem/needs identification interview (Kratochwill & Bergan, 1990; Sheridan et al., 1996), participants work together to discuss the child's strengths, identify shared concerns, and prioritize one or two specific needs to address as a consultation team. Relevant goals are established for the child, and strategies for collecting behavioral data are determined. In general, specific data should be collected to determine the actual severity of the affected child's difficulties in adjusting to classroom norms and to assess possible environmental conditions that may be contributing to the child's difficulties (e.g., seating arrangements, group size and expectations, classroom transition schedules). To obtain a comprehensive picture of the child's behaviors, data should be collected at both school and home.

#### PROBLEM/NEEDS ANALYSIS

The second stage of conjoint consultation is problem or needs analysis, during which the team (including parents, teachers, and school psychologist) reconvene for a problem/needs analysis interview (Kratochwill & Bergan, 1990; Sheridan et al., 1996). In this meeting, participants discuss the data that have been collected and explore conditions that may be related to the behavioral occurrence (i.e., antecedents and consequences). An intervention plan is then developed collaboratively, with all team members contributing their ideas and expertise (Jacobs, 2004). Emphasis is placed on procedures and strategies that are effective and acceptable in natural home and school contexts. Specific tactics are determined for addressing the affected child's difficulties at both home and school. It is imperative that all key individuals involved with the child be knowledgeable about and active in the implementation of the intervention. This will ensure consistency and continuity among care providers and maximize the child's chances for success.

#### PLAN IMPLEMENTATION

During plan implementation, the third stage of conjoint consultation, the intervention is put into place across home and school settings. All individuals who play an active part in the plan should be familiar with their specific roles and responsibilities. The school psychologist consultant is in a good position to monitor each aspect of the program to assist parents and teachers, ensuring that the plan is being implemented



as intended in both home and school. In some cases, direct training or modeling of some of the treatment components will be necessary for consultees who are unfamiliar with certain strategies. It is also important that data continue to be collected during this stage to assess the child's responsiveness to the intervention and movement toward consultation goals.

#### PLAN EVALUATION

The final stage of conjoint consultation, plan evaluation, involves determining whether the child is making progress on the specific behaviors or concerns targeted for consultation. In the treatment evaluation interview (Kratochwill & Bergan, 1990; Sheridan et al., 1996), all consultation participants meet to review the data collected prior to and during the implementation of the treatment plan. The intervention program often will require some modification; indeed, in some situations, an entirely new plan will be developed. If the initial goals for the child have been met, team members will typically recycle back through the consultation stages and address another concern facing the child. This stage is especially critical when a child's recovery or developmental progress is variable. Continuous evaluation of the appropriateness of goals for the child, and of improvement or regression surrounding those goals, is critical. It is very important at this stage to ensure that strategies are put into place to help the child maintain treatment gains that have been made.

#### ANALYSIS

Parents are often the persons most knowledgeable on issues regarding their family and their child's condition, particularly if they have been active in the recovery process following an injury or engaged with other caregiving medical or social systems. They have firsthand information about their child's temperament, motivation, responsiveness, tolerance levels, and degree of adaptation. They can provide necessary background information on the nature and course of the injury, disease, or congenital condition, adjunct services being provided, family adjustment, and their child's strengths. Partnerships with the school, particularly via consultation models that include home, school, and medical expertise, is critical to ensure consistency across caregivers and maximize achievement toward shared goals.

### FAMILY EDUCATION, ADVOCACY, AND THERAPY

In addition to supporting extensive consultation programs for families with children with neuropsychological or neurological disabilities, schools can mount a number of other helpful family-oriented programs (Livingston et al., 1985a, 1985b; Miller, 1993). Several approaches are described next. Also mentioned is the critical need for case management.

#### EDUCATION

Many families will benefit from educational programs that describe what is currently known about the learning, behavioral, social, emotional, and vocational needs of chil-

dren with disabilities. The goal of educational programs is to increase family understanding and knowledge of their affected child's situation.

Knowledge is power. Although general educational sessions are not a substitute for the specific informational needs a family has following their child's head injury or diagnosis of neurological anomaly/ the availability of regular programs sponsored by schools offers parents a chance to form relationships with educators and other related professionals.

When providing educational information, it is important that the information is shared in a manner that makes sense to nonmedical personnel, using nontechnical terms and language. Often, schools use medical-based neuropsychologists or physicians as presenters for family workshops or programs. These presenters add credibility but often speak in jargon, which defeats the goal of education as enlightenment. A well-prepared school psychologist consultant is often a great help in suggesting language that respects the family's knowledge while not overloading their ability to absorb and use information (Hamaguchi, 1995; Savage & Wolcott, 2004).

Further, all information must be shared in a manner that is sensitive to the family's vulnerability. Care should be taken not to overwhelm the family with too many facts and details about the affected child's disabilities early in the family's exploration stage. The amount of information first presented should be limited to allow family members sufficient time to process the newly acquired knowledge (DePompei & Zarski, 1989). Details about the disability and predicted course of the disorder and treatment options often need to be repeated several times. Anxiety may interfere with learning, so multiple opportunities for learning are necessary.

Lezak (1978, 1986) suggests that the following key points should be conveyed to families:

- Anger, frustration, and sorrow are natural reactions of family members when a relative is diagnosed with a disability or suffers an injury.
- Caretakers should preserve their own emotional health, physical well-being, and sanity to be of benefit to the affected child.
- Families should be informed and helped to process details surrounding the organic limitations to development or recovery.
- Recovery and development are not continuous and reliable processes. A child may show rapid recovery or achievement in some areas and during some phases of rehabilitation; in other cases, recovery or growth may be slow or absent. Accepting these realities can help families resist blaming treatment staff, medical facilities, or school personnel when their dreams for their child are not met.
- Conflict and disagreements between family members and the affected child are inevitable. Caretakers must rely on their own judgment in making decisions regarding care.
- The family role changes that are concomitant to a relative's disability can be stressful to all.
- Real limits exist pertaining to what family members can do to change the affected child's behaviors and personality. Feelings of guilt or ineptitude are normal but not realistic.

- The family ultimately may be faced with decisions about alternative living or care arrangements for the affected child.
- The family should review legal documents, and financial arrangements concerning the care of the affected child.

Families report not knowing enough about the rehabilitation process, for example, their role and appropriate expectations. If the affected child is being served by both the school system and another medical or rehabilitative system, educational events that integrate information about the multiple systems are helpful. This integration is vital for both parents and the professionals in each system. Educators express concerns similar to those of parents when they realize their students are being served in multiple systems. They want to be supportive of an array of interventions but are often uninformed as to their unique role or how their expectations support or undermine the expectations of others.

The development of a conjoint consultation plan is a good basis for introducing critical information to families and schools. For example, information on how to structure the child's leisure time, what to expect in terms of sexuality from the affected adolescent, or how to deal with externalizing behavior problems may be useful (Asarnow, Lewis, & Neumann, 1991; Black, Jeffries, Blumer, Wellner, & Walker, 1969; Slater & Rubenstein, 1987). In schools, the individualized educational planning development process can serve and support the conjoint consultation process (see Chapter 31, this volume). School psychologists with neuropsychological training or school neuropsychologists must be active and instrumental in helping the team (including parents) develop appropriate educational goals and acquire the necessary information to adequately address each child's unique difficulties.

Although workshops and regular consultations from area professionals are extremely valuable educational opportunities, schools must not overlook the importance of measuring the yearly progress of all children, and neurologically impaired children in particular. Annual meetings with parents or groups of parents allow schools to tailor educational events to both the current educational needs of the child and the developmental expectations of the parents. Although a 16-year-old may still require educational programming that is more common to elementary students, his or her parents can benefit from information about vocational possibilities and opportunities. A common failure of caregiving systems occurs when they become identified with a sole, particular focus and lose sight of an integrated understanding of family system needs.

#### FAMILY SUPPORT AND ADVOCACY

Parents face frightening burdens associated with their child's special needs. They require information about the legal and financial situations they face. They benefit from direction regarding insurance, other funding sources, and the legal help they may need to manage personal injury or compensation suits. Ongoing assistance throughout the rehabilitation period is often necessary.

Families often require a case manager to assist them in identifying and accessing all the community and educational services for which they qualify. Case managers may be effective advocates responsible for educating parents about the scope of their child's

rights under the Individuals with Disabilities Education Act. Similarly, they may serve as mediators to assist families in the procurement of necessary services. Because service needs change with the age of the child (e.g., from preschool early intervention programs to vocational rehabilitation), it is important that case managers be knowledgeable about child development and transition programs and available to families over time. Case managers are especially helpful if they also know physicians, lawyers, and rehabilitation professionals who are well-informed about neurological impairments.

Linking families with local or national organizations, such as the National Dissemination Center for Children and Youth with Disabilities (<http://nichcy.com>; 800-695-0285), the Brain Injury Association of America (<http://biasua.org>; family helpline: 800-444-6443), and Disability Resources, Inc. (in Abilene, Texas; <http://drifolks.org>), is also a very helpful way to provide them opportunities to access information about their affected child. Further, such linkages can help families cope via their own actions and through more systemic efforts, such as legislation, advocacy with school districts, or regulations affecting disabled people (Savage & Wolcott, 2004). Some settings, such as Disability Resources, Inc., are connected to faith-based efforts that are attractive to some families.

Local organizations are a source for self-help and parent support groups. Almost all families feel guilt, sadness, loss, anguish, and anger associated with their child's disabilities. Although there is no empirical research associated with self-help groups of this type, family groups can play an important role in offering support and normalizing these emotional states. Such support may serve to prevent the development of more serious family dilemmas—especially child abuse (Cross, 2004; Rosenthal & Young, 1988).

Depending on the severity of the affected child's disability, including him or her in educational sessions may be warranted. Some guidelines for this practice have been offered by DePompei and Zarski (1989) and include:

- Cover no more than two new topics in a session.
- Repeat main points on several occasions (and encourage family members to do the same) and ask the affected child for verification.
- Review the same information in more than one session.
- Model responses to the affected child for the family.

#### FAMILY COUNSELING

Family counseling is both a preventive and a remedial strategy to consider, especially if it focuses on fostering emotional resources and coping skills and if the therapist can also teach the family strategies for dealing with their child. Family members often neglect their own needs and those of other family members because of the demands of the affected child. Already mentioned is the high rate of marital disruption following the birth of a child with a disability or the injury of a child. Parents may lose sight of the call to nurture their marriage with the same intensity required by their affected child. Parents who are given this advice often agree sadly that their days are not long enough to meet everyone's needs. Romance and shared recreational times for the parents are often the first casualties in a family caring for a child with disabilities.

There is a compelling need for more empirically derived information about the effects of pediatric neurological disorders on families and about designing therapeutic

tic interventions helpful to families (Lehr, 1990; Waaland, 1990; Waaland & Kreutzer, 1988). Much of the research literature concerning neurological disorders and families is based on adult male participants (e.g., Allen et al., 1994). Often, the reports of family reorganization after the injury relate the experiences of wives and children coping with injury of a husband, or of parents (especially mothers) coping with the injury of their unmarried adult child. Results from these studies may not be directly comparable to families with pediatric clients, given the different role expectations for children in contrast to adults.

Counseling or therapy can also focus on strategies that family members can use over time to deal with the child's neurological impairment and behavioral sequelae. Families with TBI survivors often experience a rather rapid initial recovery phase, when they experience a "honeymoon" period and believe that their lives will soon be back to normal (Miller, 1993). Many find, however, that they need to acquire new skills, especially ones related to teaching and goal-setting strategies, to work with their injured son or daughter. They may have to teach their adolescent how to use the toilet and brush his or her teeth. They may have to be involved in language training. Of special importance is the family's need for strategies to cope with aggressive outbursts from the TBI survivor, as aggressiveness is a significant stressor on families (Brooks, 1984).

Counseling for siblings of children with head injuries is often recommended. For example, they can benefit from education about the possible negative effects of prolonged caretaking on themselves and on the rest of the family. Siblings have been shown to display inadequate problem solving and dysfunctional attitudes (Orsillo et al./ 1993), using coping strategies such as wishful thinking, self-blame, and avoidance at least as often as more effective, problem-focused or social support coping strategies. Depending on their age, siblings may not be verbally or emotionally mature enough to express their feelings and confusions. If this goes unrecognized, the sibling may endure significant psychological hardship.

It may also be useful to involve the affected child in family counseling sessions to the greatest extent possible. Therapeutic indications for involving the child will likely be related to his or her developmental status, level of injury, and degree of physical, cognitive, and behavioral functioning. Specific therapeutic goals might focus on helping all family members to express thoughts and concerns regarding the affected child's influence on family dynamics and exploring alternative coping skills.

## CONCLUSION

The objectives of this chapter were to outline:

- What families report to be their experiences in coping with a child with neurological difficulties
- The tasks families must navigate to promote a positive family life
- Effective and efficient consultation, education, advocacy, and counseling services that a school-based consultant might offer
- The special role the psychologist plays in meeting family needs, coordinating school and family interventions, and contributing to the cohesiveness and effectiveness of the school-based team (Barry & O'Leary, 1989)

When planning programs for neurologically impaired learners, care providers must keep in mind that the affected child is only one member of a family system (Brooks, 1991b). A growing literature of research and clinical reports documents not only the massive effects children's disabilities can have on parents, siblings, and extended family, but also the critical role a well-functioning family plays in the affected child's eventual adjustment (Jackson & Haverkamp, 1991; Kaplan, 1988; Kreutzer, Marwitz, & Kepler, 1992; Martin, 1988; Rivara et al., 1992; Rivara et al., 1993; Testani-Dufour, Chappel-Aiken, & Gueldner, 1992).

Families of learners with disabilities may experience major psychological, financial, role, and relationship risks. Difficulties for the family stem from both objective and subjective burden. Objective burden refers to objectively observable symptoms and conditions of the affected child, such as language, speech, and memory impairments. Subjective burden concerns the level of distress experienced by family members that is related to both the severity of the child's disability and features of the relative himself or herself. This may be mediated by social variables, such as the presence or absence of support networks, or the relationship between the relative and the affected child (Brooks, 1991b; Brooks et al., 1987). In general, female caregivers of persons with brain impairment report higher levels of burden. Subjective burden is more highly related to the presence of social aggression and cognitive disability in the child than to factors associated with physical disability. Further, the extent of the learner's emotional and behavioral difficulties appears to be more important than the severity of the physical impairments in predicting family members' levels of burden (Allen et al., 1994).

The difficulties experienced by the families of individuals with neuropsychological or neurological disorders are usually long lasting, and some may actually increase over time (Bigler, 1989; Bragg et al., 1992; Hall et al., 1994), especially those associated with subjective burden (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986, 1987; Brooks & McKinlay, 1983). Divorce, family conflict, substance abuse, and social isolation are possible outcomes. According to research by Mauss-Clum and Ryan (1981), the most frequently reported maternal reactions to closed-head injuries are frustration, irritability, arrogance, depression, anger, and feeling trapped. Other common responses include denial (albeit sometimes functional or misunderstood denial), anger, and overprotection (Brooks, 1991b).

It is of some importance that what families report to be valuable as they adjust to their son's or daughter's disability is valid information from caring school psychologists or school neuropsychologists as well as from other educational professionals. Although the child's disability cannot be undone, families benefit from consultation about an array of issues pertinent to coping with the child, health and educational systems, and community agencies (Miller, 1993). Consultation can greatly assist families in their continuing efforts to reorganize around the effects of meeting the needs of a special child (Katz & Deluca, 1992).

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