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## ABSTRACT

This final report describes the Traumatic Brain Injury (TBI) Home/School Support project, an Oregon project which attempted to decrease stress in parents caring for school-aged children with TBI and to provide support to schools serving students with TBI. During its 3 years of development, the project involved over 50 families of children, ages 5-21, who had experienced a severe traumatic brain injury. In addition, nearly 200 educators throughout Oregon received inservice training and technical assistance. The multi-faceted model on which the project was based included both school-centered and child-centered goals focusing on issues in instructional planning and community participation. The model provided for coordinated family services from the Oregon Head Injury Foundation, a community psychology clinic, a parent-run respite care organization, and a public school-based information and referral program. Results of the project indicated that a combination of coordinated school/home efforts, respite care, case management, and parent training and counseling were of significant assistance to the parents of children with TBI. This report has sections on the project's goals and objectives, conceptual framework, the model and its participants, logistical problems and modifications, findings, impact, and sources of further information. Extensive appendices include articles and book chapters: "A Comparison of Two Psychosocial Interventions for Parents of Children with Acquired Brain Injury: An Exploratory Study" (George H. S. Singer and others); "Comprehensive Family Support for Behavioral Change in Children with Traumatic Brain Injury" (Joseph M. Lucyshyn and others); "Helping Parents Negotiate the School System" (Ann Glang and others); "Tailoring Direct Instruction Techniques for Use with Elementary Students with Brain Injury" (Ann Glang and others); "Training an Interdisciplinary Team in Communication and Decision-Making Skills" (Elizabeth Cooley); "Using Direct Instruction with Brain Injured Students" (Ann Glang and others); and "'You Can't Imagine Unless You've Been There Yourself': A Report on the Concerns of Parents and Children with Acquired Brain Injury" (George H. S. Singer and Charles Nixon). A retreat planning outline, a knowledge quiz, and a teacher questionnaire are also attached. (Contains approximately 190 references.) (DB)



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ED 387 965

# INTERNATIONAL READING FOR EARLY LIFE AND GROWTH WITH TRAUMATIC BRAIN INJURY

FINAL REPORT

IR & ERIC 0023

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March 1993

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HOME/SCHOOL SUPPORT FOR FAMILIES AND CHILDREN

WITH TRAUMATIC BRAIN INJURY

FINAL REPORT

Severely Handicapped Division  
U.S. Department of Education  
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## II. Abstract

The TBI Home/School Support project was a multi-faceted model for delivering support services to families who are living with children and youth with traumatic brain injuries. During its three years of development, the project involved over 50 families of children ages 5-21 who had experienced a severe traumatic brain injury as a result of a motor vehicle accident, fall, or some other source of trauma. In addition, nearly 200 educators throughout Oregon received inservice training and technical assistance from the project. The central goal of the project was to decrease the severe familial stress resulting from having a child who is traumatically brain-injured (TBI). The model also included school- and child-centered goals that focus on issues in instructional planning and community participation.

The model provided for coordinated family services from: the Oregon Head Injury Foundation; a community psychology clinic; a parent-run respite care organization; and a public school-based information and referral program. These components have empirical foundations in our previous research and demonstration work (Singer & Irvin, 1989). This project was an effort to evaluate this same empirically validated model with a different and rapidly growing population: families who have school-aged children with traumatic brain injury (TBI).

The results of our work on the TBI Home/School Support project suggest that a combination of coordinated school/home efforts, respite care, case management, and parent training and counseling can be of significant assistance to parents of children with TBI. Additionally, parents perceive that family support components are both important and successful in assisting them.

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## Project Context

Each year, approximately 165,000 children and youth survive brain injuries sustained in motor vehicle accidents, falls, sports, and physical abuse (Bush, 1986). Of these children, 20,000 will be left with long-lasting alterations in social, behavioral, physical, and cognitive functioning (Kalsbeek, McLaurin, & Harris, 1980; Rosen & Gerring, 1986). The effects of brain injury vary greatly depending on a range of factors such as length of coma, location of injury, pre-injury personality, and academic history. In the majority of cases, school performance and social functioning are permanently altered following TBI (Begali, 1987). Even children with mild brain injuries are usually placed in special classes or retained one year (Klonoff, Low, & Clark, 1977; Fuld & Fisher, 1977). More severely injured students will require a range of special services once they return to school.

Students with traumatic brain injury pose new challenges for educators committed to providing appropriate instructional programs for all students. School personnel must address a range of issues specific to brain injury that they have never faced before.

### Impact on Families

The effects of traumatic brain injury often give rise to severe familial stress and resultant psychosocial distress in other members of the family (Prigatano, 1986; Brooks et al., 1986; Lezak, 1986; Livingston, Brooks, & Bond, 1985; Frye, 1987; Livingston, 1987; Lezak, 1988). Surveys and clinical reports have repeatedly found that the most distressing effects are changes in the child or adolescent's social behavior (Frye, 1987; Livingston, 1987). For example, Brooks et al. (1986) found that the greater the behavioral and personality changes in the injured child, the greater the subjective burden reported by parents. Unfortunately, the picture for families does not improve with time; familial distress is both progressive and enduring (Lezak, 1988). As the caregiver becomes more disheartened and discouraged at seemingly endless and thankless work, the injured person may become more demanding and coercive. Brooks et al. (1986) have reported that at five years after the trauma, caregivers often indicated that the injured person's problem behaviors had become more severe.

Demographic and economic factors. The problems of caregiving families are not limited solely to social and psychological factors. Trends in the larger social context of the society also have an impact on caregiving families. Current demographic and economic trends can have a stressful effect on caregiving families. Primary caregivers are overwhelmingly female, usually mothers, who are increasingly likely to be either single, poor, or employed during the day and occupied as caregivers after work. The number of children in families has declined steadily during the past two decades. As a result, the number of family members available to help with caregiving has gone down, placing more demands on the primary caregiver. Similarly, geographic mobility has scattered extended families so that other relatives are less available to help.

Summary. A child's traumatic brain injury is a life-long problem (Kolb & Whishaw, 1980). Although the child may regain many skills and abilities over time, most

research suggests that families do not cope well with the stress of TBI; as time passes, psychosocial disturbance in the family increases rather than decreases (Brooks et al., 1986).

#### IV. Project Goals and Objectives

The primary goals of the Home/School Support project were to: 1) decrease stress in parents caring for school-aged children with TBI, and 2) provide support to schools serving students with TBI. The specific objectives were as follows:

- 1) To create a replicable model
- 2) To deliver services to families in the following areas:
  - stress management training
  - behavioral parent training
  - behavioral counseling
  - case management to obtain needed services
  - volunteer assistance
  - assistance with educational program
- 3) To evaluate the model and its components
- 4) To disseminate findings

#### V. Conceptual Framework

The TBI Home/School Support model was developed to assist parents in coping with the life-long stress of caring for a child with TBI. The model has five major components: a) assistance with educational planning and educational interventions; b) direction service case management; c) respite care and volunteer assistance, d) parent counseling and therapy, and e) parent training. Each component of the model was developed from results of previous research conducted by the principal investigators or by other behavioral and neuropsychological researchers. The major contribution of the proposed project was to demonstrate the effectiveness of these family service components when they are used to provide long-term follow-along services for children with TBI and their families so that children are effectively re-integrated into home, school, and community activities. In this discussion, we describe the theoretical and empirical basis for each component of the model.

##### Model Component 1 (Home/School-Based) Assisting Parents and Teachers with Educational Programs:

Although most schools have experience working with students with varying handicapping conditions, the needs of students with TBI are fundamentally different from those of other students typically served in special programs (Cohen, Joyce, Rhoades, & Welks, 1985; Savage, 1987a). If a student's school re-entry is to be a positive one, teachers, principals, school nurses, and other school staff need to be

educated about the special needs of the head-injured student (Marlowe, 1987; Savage; 1987a, 1987b).

Inservice alone may not provide teachers with sufficient information to effectively teach children with TBI. Research in staff development suggests that coaching, i.e., in-vivo assistance from an expert with the implementation of new skills and strategies, is an effective way to ensure that teachers transfer new teaching skills and strategies into their classroom repertoire (Carnine & Gersten, 1985; Joyce & Showers, 1981). Unless teachers receive some follow-up training once they are in the classroom they are unlikely to use the new skills they have learned (Fullan, 1983).

#### Model Component 2 (School/Community-Based): Direction Services Case Management

Traumatic brain injury draws families into sudden and prolonged interaction with several social systems that may previously have been irrelevant to family members. The sudden onset of the injury plunges family members into the world of emergency rooms, intensive care units, and rehabilitation units of the medical system. As the child or adolescent moves to outpatient status, the public schools become an important focal point for rehabilitation, respite, and social networking. The prolonged needs of youth with TBI usually necessitate involvement with vocational rehabilitation, residential, income maintenance, recreation, and transportation agencies.

Direction Service is an agency whose aim is to "put the pieces together" by providing a network of centers whose primary purpose is to assist parents in locating and selecting an appropriate mix of services from existing agencies. The Direction Service for Lane County, Oregon has served over 900 families since 1977. It is currently funded predominantly by the Lane County Educational Service District, the local intermediate education agency responsible for services to children with disabilities.

In order to document the service linkages, and parents' satisfaction with them, we have established a computerized data collection system for Direction Service of Lane County, Oregon. Our preliminary data from the computerized case management records and from social validation assessments affirm the earlier work by Zeller (1980), and attest to the value of Direction Service case management as a family support service. In effect, a single service agency serves as a gateway to a multitude of generic community services. Because of the established value of this service, it is an important component of this collaborative model.

#### Model Component 3 (Community-Based): Respite Care and Volunteer Assistance

Surveys of parents of children with disabilities often document respite care as the single most desired service for family support (Agosta & Bradley, 1985; Salisbury & Griggs, 1983). The need for respite is particularly acute for the growing population of single mothers of children with disabilities (Vadasy, 1986). Respite permits parents and siblings to engage in activities on their own for rest and recreation.



The TBI Home/School Support project's respite care program was based on a training approach developed by Neef, Parrish, Egel and Sloan (1985). In this model, respite care is: responsive to family needs, competency-based, cost-effective and practical. The skill areas in which respite care providers are trained include: 1) preparation/information/parent interaction, 2) child behavior, 3) physical/medical management, and 4) emergencies.

In our previous work at Oregon Research Institute, we have provided respite care to families through the use of community volunteers. A volunteer is linked with the child with disabilities and spends time in community activities with the child on a weekly basis. In our evaluation of participating parents' views of the value of volunteers and their satisfaction with volunteer services, we found that parents consistently viewed the volunteer program as valuable and effective in meeting its goals (Cooley & Singer, 1989). The use of volunteers has proven to be a successful way to increase the rate of participation of children with severe disabilities in community activities.

#### Model Component 4 (Home/Community-Based): Parent Training

Parents frequently report that one of their greatest stressors is aberrant behavior by their child with disabilities (Brooks et al., 1986; Singer, Irvin, & Hawkins, 1986). Since many of the major stressors experienced by parents of children with TBI are child-centered, it is essential that parent support services assist parents to manage aberrant behavior and increase adaptive prosocial behavior of their children. Thus, the underlying goal of this component is to decrease parental stress so that children may participate in school and community activities.

Behavioral parent training for parents of children with and without disabilities has been studied widely (Dangel & Polster, 1984; Sanders & Dadds, 1982; Sanders & Glynn, 1981; Sanders & James, 1983). Parents have been trained successfully to modify children's aberrant behavior, and to teach a variety of independent living skills to their handicapped children (Baker, 1984). The content of behavioral parent training is a body of techniques developed by social learning and applied behavior-analytic researchers (e.g., Dangel & Polster, 1984; Tavorima, 1975). In our work with parents of children with severe disabilities, we have shown that generalization of parent behavior changes can be obtained via group training, and that parents can learn to modify some problem behaviors of some children with severe disabilities (Singer, Irvin, & Hawkins, 1988).

#### Model Component 5 (Home/Community-Based): Enabling and Empowering Parents Through Skill-Based Counseling

Parent counseling has been described as an essential support service for family members following a traumatic brain injury in the family (Lezak, 1978, Prigatano, 1986, Shapiro, 1983). Counseling services are usually described as either group support or emotional counseling (Shapiro, 1983; Wright, Granger, & Sameroff, 1984). Parent support groups are intended primarily to reduce feelings of isolation by allowing parents to share common experiences. They have had widespread popularity, although there is little empirical documentation of their efficacy (Shapiro, 1983). Emotional counseling is

usually described as aimed at helping parents through presumed stages of grieving following the trauma (Wright, Granger, & Sameroff, 1984). Again, the efficacy of this kind of counseling has not been established empirically. However, clinical case reports suggest that it is important in assisting parents through the phases involved in adaptation to TBI (e.g., Lezak, 1988a).

Coping skills for the long term: stress management. In our work at ORI (Singer, Irvin, & Hawkins, 1988), we have emphasized the importance of assisting parents and siblings to reduce family stress as it arises over long periods of time. During the past decade, behavioral researchers have developed a variety of cognitive-behavioral treatments for persons suffering such diverse stress-related symptoms as generalized anxiety, chronic headaches, ulcers, asthma, and insomnia (Deffenbacher & Guinn, 1982; Goldberger & Breznitz, 1982; Woolfolk & Lehrer, 1984).

Singer (1985) and Singer, Irvin, & Hawkins (1988) evaluated the effectiveness of a cognitive behavioral approach for stress management with parents of children with severe disabilities. Following a 10-week class, parents in the stress management group reported significantly lower levels of stress and depression. These differences were maintained at the one year follow-up.

Short-term behavioral therapy for demoralization. In our work with parents, we have found that individualized short-term behavioral therapy following group stress management treatment has been effective for those individuals with elevated levels of depressive symptomology and/or anxiety (Biglan & Singer, 1986). The therapy is based on an extensive empirical literature of a problem-specific approach to teaching people skills for dealing with stress and the problems that accompany it (Biglan & Dow, 1981; McLean & Hakstian, 1979).

## VI. Description of the Model and Participants

In this section we describe each component of the TBI Home/School Support model. In addition to the components described in our original proposal, we also include here those services that were added in response to the needs expressed by families.

### Model Component 1 (Home/School-Based): Assisting Parents and Teachers with Educational Programs

The TBI Home/School Support project provided several types of support and information to families and schools. To qualify for services all children whose parents or school were involved met the following criteria: 1) documented brain injury with a coma of 24 hours or more, and 2) significant disabilities in 2 of the following 3 areas: cognition (2 or more years below grade level), behavior, or physical abilities.

Inservice. Although most schools have experience working with students with varying handicapping conditions, the needs of students with TBI are fundamentally

different from those of other students typically served in special programs (Cohen, Joyce, & Rhoades, & Welks, 1985; Savage, 1987a). Educators need specific information about the cognitive and behavioral effects of TBI.

Project staff presented seven inservice presentations for districts throughout Oregon over the course of the three year project. The focus of the inservices was on the effects of TBI on the child's school experience. Specific information about a particular student was included for those staff working directly with the student.

As a result of teachers' response to the project's local inservices, Drs. Glang and Cooley were asked to coordinate a series of state-wide inservices in the winter and spring of 1993. In conjunction with the State of Oregon's Regional Services System and Sacred Heart Hospital's Oregon Rehabilitation Center, Drs. Glang and Cooley conducted day-long inservices for educators and related service providers in each of the state's six regions. Attendance at each session ranged from 25-75 participants. Participants included classroom teachers, special educators, speech therapists, occupational therapists, physical therapists, nurses, parents, administrators, and staff from community agencies. Topics covered in the workshops included: 1) Overview of TBI, 2) Academic Programming, 3) Supporting Families, 4) Behavior Management Strategies, and 5) Social Integration.

Consultation with school teams serving students with TBI. The school team, including classroom teacher, special educator, paraprofessional, and related service providers need more detailed information about TBI and its effects on cognition and behavior than the school-wide inservice can provide. Those staff with direct teaching responsibilities were also be informed of strategies for improving acquisition, generalization, and maintenance of skills. This component of the model provided consultation and individualized, technical assistance to teachers so that students learned, generalized, and maintained the skills they were taught. Ongoing support was also provided to ensure that teachers felt comfortable with the new strategies.

The project provided consultation to teachers working with 11 students with TBI. Teachers of four of the students received intensive weekly or bi-weekly consultation for 6-9 months to assist them in designing and implementing the instructional program. In each case, project staff provided in-class technical assistance.

#### Model Component 2 (School/Community-Based): Direction Services Case Management

This component of our model, case management, addressed the problems of discontinuity, systems complexity, and systems dispersal in serving students with TBI. Direction Service, a locally funded organization providing case management and referral services, served a central role in linking and coordinating the various community agencies that provide support to families of children with TBI. Direction Service was involved in three areas: a) to provide continuity between the medical setting of the in-patient rehabilitation facility and the public schools b) to provide service linkage based upon family needs assessment; and c) to assist parents with I.E.P. development in the public schools. Direction Service staff worked with 10 families over the three year project. In

addition, as an outcome of the project, Direction Service expanded its services to include a counseling center for families of children with disabilities.

### Model Component 3 (Community-Based): Respite Care and Volunteer Assistance

Family members who are the primary caregivers of a child with TBI must take time out to take care of themselves if they are to continue caring for their child. Respite care, in conjunction with the other components described in this proposal, may help families avoid the physical and emotional illnesses experienced by many families with brain-injured members documented by Oddy, Humphrey, and Uttley (1978a). Providing respite care for families is also a kind of social service that could be widely adapted in communities that have universities and colleges, and could serve as a means for helping communities become more aware of brain injury.

In the Home/School Support project, we recruited, trained, and monitored five volunteers who spent time weekly with students in our project. Each volunteer was a college student who obtained course credits for their participation in the project. Students devoted an average of three hours per week to engaging the child in integrated, age-appropriate community activities.

At the conclusion of the project, the local Association for Retarded Citizens (ARC) integrated the TBI Volunteer Assistance program into their ongoing program. As part of the program, ARC staff provided training and support to community volunteers working with children and adolescents with a variety of disabilities.

### Model Component 4 (Home/Community-Based): Parent Training

Group behavioral training has been used for teaching parents how to reduce aberrant behavior in moderately and severely handicapped children (Hornby & Singh, 1984; Mash & Terdal, 1973, Singer, Irvin, & Hawkins, 1986; Tavorima, 1975). Based upon this research, the TBI Home/School Support project delivered group behavior management training to parents of children and adolescents with TBI. The training included generalized strategy training to increase the probability that parents use the skills they learn in the training.

Two groups of parents participated in the behavioral parent training. The first group, in Eugene, consisted of 7 parents, and the replication group, held in Portland included 12 parents. In some cases, both parents participated in the group, and in others, only one parent attended the weekly session. The 10 week session included training in social learning principles and behavior analytic skills. Skills covered included using clear instructions, positive reinforcement, prompting, and non-physical aversives. Parents participated in discussions about the skills and watched videotaped examples of parenting techniques. Parents were given weekly homework assignments to practice specific behavioral skills in the home. In order to facilitate compliance with the assignments, a staff member telephoned parents once a week to discuss the assignments.



### Model Component 5 (Home/Community-Based): Enabling and Empowering Parents Through Skill-Based Counseling and Support Services

The Home/School Support project provided four forms of support/counseling experiences for parents: group stress management training, individual counseling, parent support group, and a weekend retreat. Each is described below.

Group stress management training. The stress management training employed a cognitive behavioral approach to stress management. Two groups of parents (Portland, N = 12; Puyallup, WA, N = 7) participated in the 10 week treatment. All were parents of children and adolescents who had experienced severe TBI. Parents practiced the use of a modified form of Progressive Muscle Relaxation (Goldfried & Trier, 1974; Woolfolk & Lehrer, 1984), self-monitoring, and cognitive restructuring (Goldfried & Goldfried, 1975). Each class consisted of a brief lecture, practice of a specific skill, and a group discussion of homework.

Individual and family counseling. During the three years of the project, the Home/School Support project supported counselors at ORI's Center for Caregiving Families to provide mental health services for children with TBI and their families. Individual and family counseling was provided to 11 families (a total of 84 hours of counseling). The child issues addressed were anger management, lack of social skills, risk taking, relationships with siblings and parents, learning problems, behavioral problems, hyperactivity, and problems related to organizing, planning, and problem solving.

Parent support group. Parents who participated in our initial Behavior Management training session felt that their needs could best be met by more informal support networks. In response to this feedback, project staff created a parent support group. Over a 6 month period, 15 parents attended 10 two-hour group meetings. Some of the group sessions were thematic. Themes included: family adjustment to TBI, sibling issues, behavior management, stress management, neuropsychological assessment, family recreation, and the future for our children. Guest speakers presented on several occasions. One event consisted of all the parents and their family members going bowling together.

Weekend retreat. In response to the issues and needs that came to our attention in group and individual counseling, the TBI Home/School Support project sponsored a weekend retreat for parents of children with TBI in May, 1992. The purpose of the retreat was to provide an opportunity for parents to meet one another in an informal, relaxed setting while learning some skills and techniques that are helpful in coping with the effects of TBI. Twenty-five parents participated in the weekend retreat. In addition to having opportunities to socialize with other families, parents attended group sessions in the following areas: 1) Dealing with emotions and grief, 2) Effects of TBI on the family, 3) Sibling issues, 4) Peer relationships, 5) Educational program concerns, 6) Coping with TBI from a family perspective, 7) Accessing community resources, and 8) Planning for your child's future.

## VII. Methodological or Logistical Problems and How They Were Addressed

In our original proposal, our evaluation plan called for an assessment of the efficacy of our entire model. As we worked with families and schools, we realized that a summative evaluation of the complete model made less sense than originally envisioned. Families and schools, we realized, could best benefit from our model if it was offered to them as a menu of services from which to select. One family, then, might benefit from participating in the stress management training, while another family needed marital counseling. While one school district needed inservice training for all staff, another needed in-depth consultation for a team of educators working with one particularly challenging student.

The primary departure from the original proposal involved modifying our evaluation plans. Rather than evaluate the entire model as a whole, we conducted in-depth studies that investigated the relative efficacy of the components rated as most valuable by families and school professionals. These studies are presented in Section IX.

Over the course of the three years of the project, we encountered several opportunities to expand our model and investigate areas that became of interest as we worked more closely with families and schools. Each of these opportunities required that we slightly modify our original plans.

The first modification, the only one which required adding a new objective and related activities, occurred during the second year of the project. As we consulted in schools, we became increasingly aware that students with TBI are usually served by *teams* of educators. For each student we worked with, a multi-disciplinary team was nearly always involved (generally including a special educator, classroom teacher, paraprofessional, OT, PT, and Speech/Language Therapist). As we observed teams struggle with the multitude of challenges in serving students with TBI, we became interested in evaluating approaches to improving team functioning. Thus, in the third year of the project, we worked closely with a team of professionals to study how best to help teams work effectively. This study, conducted over a 6 month period, is described in detail in the article by Dr. Cooley ("Training an Interdisciplinary Team in Communication and Decision-Making Skills") in Section IX of this report.

As we worked more closely in school settings, we became acutely aware of the lack of empirical basis for most instructional strategies suggested for students with TBI. Another modification involved adding a study to evaluate the relative effectiveness of an instructional system used widely with students with disabilities. During the second year of the project, we conducted a study with three students with severe TBI, to evaluate the effectiveness of Direct Instruction procedures in teaching academic and behavioral skills (see Section IX, "Tailoring Direct Instruction techniques for use with elementary students with brain injury").

Finally, Drs. Singer and Nixon had the opportunity to interview 15 sets of parents about their experiences coping with the challenges of TBI. These interviews led to a qualitative study of parenting a child with severe TBI. This study, described in the

chapter, "You can't imagine unless you've been there yourself," (see Section IX) presents the challenges associated with TBI from the parent's perspective, and serves as a foundation for our model's findings.

### VIII. Project Findings

The results of our work on the TBI Home/School Support project suggest that a combination of coordinated school/home efforts, respite care, case management, and parent training and counseling can be of significant assistance to parents of children with TBI. Additionally, parents perceive that family support components are both important and successful in assisting them.

Three components of the Home/School Support project were evaluated empirically: stress management training, interventions for improving team functioning, and using Direct Instruction to improve academic and behavioral performance. These three studies are described in detail in Section IX.

The following section summarizes other major findings from the project.

#### Statewide inservices

In the winter and spring of 1993, Drs. Glang and Cooley presented a series of six statewide inservices on the effects of TBI on school, family, and child. The topics covered in the workshops included: 1) Overview of TBI, 2) Academic Programming, 3) Supporting Families, 4) Behavior Management Strategies, and 5) Social Integration. Participants included 183 educators and related service providers in both rural and urban areas throughout the state. Table 1 presents information about the workshop participants.

Table 1. Job titles and experience of participants at inservices on traumatic brain injury

<u>Job Title</u>	<u>Number of participants</u>
Speech/Language	30
Special Ed./Chapter I	23
School Psychologist	16
Educational Asst.	12
Regular Educator	12
Occupational Therapist	11
School Nurse	10
Administrator	5
<u>Other Consulting or Itinerant Staff</u>	<u>64</u>
TOTAL	183
Average number of students with TBI worked with	1.7

Participants completed several measures in conjunction with the day-long workshop. Prior to the beginning of the workshop, participants completed a knowledge quiz about TBI and a questionnaire designed to assess their perceived competence in working with students with TBI. At the end of the day, participants rated their satisfaction with the workshop.

### Results

Figure 1 depicts the results from the knowledge quiz and questionnaire. Results indicate that respondents scored moderately low on the measure of knowledge (mean score was 71%). When these same educators were asked to rate how prepared they felt to meet the needs of students with TBI (on a scale of 1 - 5, 1 = not at all prepared, 5 = very prepared) the average rating was between 2.9 - 3.3, or only "somewhat prepared." Ratings were consistent across behavioral, academic, social, and cognitive domains. As a group, regular educators consistently rated themselves as feeling less competent than did special educators and other consulting and administrative professionals. An interesting finding showed that for this group of educators, knowledge and perceived competence were negatively correlated; those professionals who scored highest on the knowledge quiz reported feeling the least competent.

Figure 2 shows participants' rating on the social validation measure. The results indicate that the educators felt that the workshop's goals were very important and that the workshop was highly successful in meeting the goals.

### Parent retreat

In response to parents' requests for more informal parent to parent networking, the project sponsored a weekend retreat for parents of children with TBI in May 1992. Twenty-five parents attended the two day retreat. Project staff facilitated discussions and presented information in these areas: 1) Dealing with emotions and grief, 2) Effects of TBI on the family, 3) Sibling issues, 4) Peer relationships, 5) Educational program concerns, 6) Coping with TBI from a family perspective, 7) Accessing community resources, and 8) Planning for your child's future.

At the end of the retreat parents completed a social validation measure to assess their satisfaction with the retreat. As Figure 3 shows, parents were highly satisfied with the project goals and the retreat's success in meeting them. Participants felt that the workshop's goals were important (average ratings all exceeded 3.2, moderately important). Participants also felt that each of the goals was successfully met (average ratings exceeded 3.0, moderately).



## TBI Knowledge and Perceived Competence by Job Title

Job Title	N	TBI Knowledge Quiz Score 0% to 100%	Perceived Competence				
			Physical Needs	Social/ Behavioral	Cognitive	Instructional	Peer Relationships
Special Education Teachers	35	63	3.3	2.9	3.0	3.3	3.0
Regular Education Teachers	12	71	2.3	2.5	2.2	2.7	2.7
Others	143	73	3.4	2.9	3.1	3.0	2.9
<b>TOTAL</b>	<b>190</b>	<b>71</b>	<b>3.3</b>	<b>2.9</b>	<b>3.0</b>	<b>3.1</b>	<b>2.9</b>

Figure 1. Results of Knowledge Quiz and Preparedness Questionnaire from TBI workshops.

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Figure 2. Social Validation Results From TBI

Workshops For Educators

(Scale: 4 = Highly, 3 = Moderately, 2 = Mildly, 1 = Not at all)

<u>RETREAT GOALS:</u>		N	SD	$\bar{X}$
I.	<u>To provide participants with an overview of traumatic brain injury, its causes, effects, and incidence rates.</u>			
A.	How important is this as a goal?	141	.44	3.84
B.	How successful was the workshop in meeting this goal?	141	.47	3.77
II.	<u>To provide participants with an understanding of academic problems commonly faced by students with TBI, and guidelines for addressing them.</u>			
A.	How important is this as a goal?	137	.41	3.85
B.	How successful was the workshop in meeting this goal?	137	.64	3.46
III.	<u>To provide participants with an understanding of effects of TBI on the family, and guidelines for working with parents more effectively.</u>			
A.	How important is this as a goal?	138	.35	3.86
B.	How successful was the workshop in meeting this goal?	134	.65	3.41

		N	SD	$\bar{X}$
IV.	<u>To provide participants with an understanding of behavioral difficulties that students with TBI often experience, and approaches for addressing them.</u>			
A.	How important is this as a goal?	141	.22	3.95
B.	How successful was the workshop in meeting this goal?	141	.52	3.61
V.	<u>To provide participants with an understanding of factors contributing to the social isolation that students with TBI often experience, and strategies for enhancing social integration.</u>			
A.	How important is this as a goal?	135	.29	3.93
B.	How successful was the workshop in meeting this goal?	134	.55	3.69
VI.	<u>To provide opportunities for participants to discuss and apply information throughout the workshop.</u>			
A.	How important is this as a goal?	135	.61	3.61
B.	How successful was the workshop in meeting this goal?	135	.60	3.62
VII.	<u>To present information in an organized, enjoyable fashion.</u>			
A.	How important is this as a goal?	136	.33	3.88
B.	How successful was the workshop in meeting this goal?	136	.60	3.59
VIII.	<u>To provide information participants with useful written materials and resources.</u>			
A.	How important is this as a goal?	135	.26	3.93
B.	How successful was the workshop in meeting this goal?	135	.38	3.85

Figure 3. Social Validation Results From Family Retreat.

Parent Evaluation of Family Retreat (N = 25)

(Scale: 4 = Highly, 3 = Moderately, 2 = Mildly, 1 = Not at all)

RETREAT GOALS:		$\bar{x}$	SD
I.	<u>To provide parents of children with brain injuries an opportunity to get to know each other and informally socialize together.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.7	.6
II.	<u>To provide parents with a relaxing break in a pleasant environment.</u>		
A.	How important is this as a goal?	3.9	.3
B.	How successful was the retreat in meeting this goal?	3.7	.5
III.	<u>To provide information about how other families have coped successfully with the effects of brain injury.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.3	.6
IV.	<u>To provide helpful information for planning your child's future.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.0	.8
V.	<u>To provide information about accessing community resources.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.8	.4
VI.	<u>To provide information about and opportunities to discuss strategies for dealing with emotions and grief.</u>		
A.	How important is this as a goal?	3.5	.8
B.	How successful was the retreat in meeting this goal?	3.1	.8
VII.	<u>To provide information about and opportunities to discuss sibling issues.</u>		
A.	How important is this as a goal?	3.2	1.0
B.	How successful was the retreat in meeting this goal?	3.1	.8



		$\bar{x}$	SD
VIII.	<u>To provide information about and opportunities to discuss effects of brain injury on the family.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.7	.5
IX.	<u>To provide information about and opportunities to discuss educational concerns.</u>		
A.	How important is this as a goal?	3.8	.4
B.	How successful was the retreat in meeting this goal?	3.4	.7
X.	<u>To provide information about and opportunities to discuss peer relationships.</u>		
A.	How important is this as a goal?	3.6	.8
B.	How successful was the retreat in meeting this goal?	3.3	.6
XI.	<u>To provide structured as well as informal opportunities for parents to interact.</u>		
A.	How important is this as a goal?	3.7	.5
B.	How successful was the retreat in meeting this goal?	3.8	.5
XII.	<u>To present information in an organized fashion.</u>		
A.	How important is this as a goal?	3.6	.8
B.	How successful was the retreat in meeting this goal?	3.7	.5
XIII.	<u>To provide parents with useful written materials in the form of a Family Resource Notebook.</u>		
A.	How important is this as a goal?	3.8	.5
B.	How successful was the retreat in meeting this goal?	3.9	.4

## IX. Project Impact

The best reflection of overall project activities and findings is in the various products that have been written over the past 6 years to disseminate our findings. This section presents all of the books, articles, presentations, and professional development activities in which key findings are featured, including copies of each where appropriate.

### A. Books

Singer, G.H.S., Glang, A.E., & Williams, J., Eds. (in press). Families and Children with Acquired Brain Injury: Challenge and Adaptation. Baltimore: Paul H. Brookes.

Glang, A.E., & Singer, G.H.S., Eds. (in press). Children with Acquired Brain Injury: The School's Response. Baltimore: Paul H. Brookes.

### B. Articles Appearing in Journals and Books

Cooley, E.A. (1994). Training an interdisciplinary team in communication and decision-making skills. Small Group Research, 25 (1), 5-25.

Cooley, E. & Singer, G.H.S. (1991). On serving students with head injuries: Are we reinventing a wheel that doesn't roll? Journal of Head Trauma Rehabilitation, 6(1), 47-55.

Glang, A., Todis, B., Moore-Sohlberg, M., & Reed, P. (in press). Helping parents negotiate the school system, in G. Singer, A. Glang, and J. Williams (Eds.) Families and Children with Acquired Brain Injury: Challenge and Adaptation. Baltimore: Paul H. Brookes.

Glang, A., Singer, G., Cooley, E., & Tish, N. (1992). Tailoring Direct Instruction techniques for use with elementary students with brain injury. Journal of Head Trauma Rehabilitation, 7(4), 93-108.

Glang, A., Singer, G., Cooley, E. & Tish, N. (1991). Direct Instruction: Applications with students with brain injury. Association for Direct Instruction News, 11(1), 23-28.

Lucyshyn, J., Nixon, C., Glang, A., & Cooley, E.A. (in press). Comprehensive family support for behavioral change in children with traumatic brain injury. In G. Singer, A. Glang, and J. Williams (Eds.) Families and Children with Acquired Brain Injury: Challenge and Adaptation. Baltimore: Paul H. Brookes.

Singer, G., Glang, A., Nixon, C., Cooley, E. Kerns, K. Williams, D, & Powers, L. (1994). A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. Journal of Head Trauma Rehabilitation, 9(4), 38-49.

Singer, G.H.S. & Nixon, C., A report on the concerns of parents of children with ABI (in press). In G. Singer, A. Glang, and J. Williams (Eds.) Families and Children with Acquired Brain Injury: Challenge and Adaptation. Baltimore: Paul H. Brookes.

Singer, G.H.S. & Powers, L. (in press). Stress management training to help parents adapt to a child's ABI. In G. Singer, A. Glang, and J. Williams (Eds.) Families and Children with Acquired Brain Injury: Challenge and Adaptation. Baltimore: Paul H. Brookes.

### C. *Presentations at Major National/International Conferences*

Cooley, E. & Glang, A. Addressing the unique needs of students with traumatic brain injury. Council for Exceptional Children. San Antonio, TX: April, 1993.

Glang, A. Effective instructional interventions for students with traumatic brain injury. Invited speaker. Pediatric Brain Injury: Looking Ahead to Adolescence and Beyond. Vancouver, B.C.: March, 1993.

Glang, A. & Cooley, E. Designing effective services for students with traumatic brain injury, their families, and professionals who serve them. The Association for Persons with Severe Handicaps. San Francisco: November, 1992.

Glang, A. & Cooley, E. Technology transfer: Adapting Direct Instruction techniques for use with students with brain injury. Association for Behavior Analysis. San Francisco: May, 1992.

Glang, A., Cooley, E., & Kurlychek, R. Tailoring Direct Instruction techniques for use with students with brain injury. Presented at annual meeting of the International Neuropsychology Society. San Diego, CA: February, 1992.

Glang, A., Cooley, E., Singer, G., & Nixon, C. Evaluation of a home/school model for serving children with TBI, their families, and the professionals who serve them. National Head Injury Foundation. Los Angeles, CA: December, 1991.

Glang, A., & Singer, G.H.S., 1990. Comparison of two instructional procedures for facilitating acquisition and retention in severely brain injured subjects. Presented at annual meeting of the National Head Injury Foundation. New Orleans, LA: November, 1990.

Nixon, C. Working with parents of children with TBI. Invited speaker. Pediatric Brain Injury: Looking Ahead to Adolescence and Beyond. Vancouver, B.C.: March, 1993.

#### D. *Presentations at Regional and State Conferences*

Glang, A. What works: Applying effective instructional methods in brain injury rehabilitation. Invited speaker. Presented at Cognitive Rehabilitation: From Attention to Executive Function. Oregon Rehabilitation Center, Eugene, OR: April, 1993.

Glang, A. & Lorch, W. Teaching students with TBI: Strategies that work. Invited speaker, Oregon Head Injury Foundation. Salem, Oregon: October, 1992.

Glang, A. & Cooley, E. Serving students with traumatic brain injury: What works? Invited speaker, Oregon Council for Exceptional Children. Seaside, OR: March, 1992.

Glang, A., Cooley, E., Singer, G., & Nixon, C. Evaluation of a home/school model for serving children with TBI, their families, and the professionals who serve them. National Head Injury Foundation. Los Angeles, CA: December, 1991.

Glang, A. Development and implementation of effective instructional programs for students with TBI. Invited speaker, Oregon Head Injury Foundation. Portland, OR: September, 1991.

Glang, A. Comparison of two instructional procedures for facilitating acquisition and retention in severely brain injured subjects. Presented at Pediatric Rehabilitation: The Impact of Traumatic Injury on Children. Glenden Beach, OR: April 1990

Glang, A. Individual education programs for students with TBI: Development and implementation. Invited speaker, presented at Coming Home: Meeting the Needs of Children with Traumatic Brain Injuries. Seattle, WA: April 1989

#### E. *Other Professional Development Activities*

On May 6, 1993, Dr. Nixon was part of a three person panel which made a presentation entitled, "Families of Students with TBI" on the Oregon Ed-Net System. The presentation was 90 minutes long and was sponsored by the Oregon Department of Education. The Ed-Net System is a video broadcasting system that connects all the educational districts in Oregon for continuing education purposes, and it has the capability of allowing participants in each participating school district to interact and ask questions of the presenters. The presentation was videotaped so that it could be used again for training of school staff.

## X. Assurance Statement

A copy of this final report has been sent to the ERIC Clearinghouse on the Handicapped and Gifted, the Western Regional Resource Center, and the National Head Injury Foundation's Education Department.



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## APPENDIX A

### Articles and Book Chapters

- A Comparison of Two Psychosocial Interventions for Parents of Children with Acquired Brain Injury: An Exploratory Study
- Comprehensive Family Support for Behavioral Change in Children with Traumatic Brain Injury
- Helping Parents Negotiate the School System
- Tailoring Direct Instruction Techniques for Use with Elementary Students with Brain Injury
- Training an Interdisciplinary Team in Communication and Decision-Making Skills
- Using Direct Instruction with Brain Injured Students
- "You Can't Imagine Unless You've Been There Yourself": A Report on the Concerns of Parents of Children with Acquired Brain Injury

**A Comparison of Two Psychosocial Interventions  
for Parents of Children with Acquired Brain Injury:  
An Exploratory Study**

# A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study

Parents of children with acquired brain injury experience severe stress. Many experience periods of emotional distress related to their child's injury and its sequelae. This study compared two kinds of support groups for parents of children with sequelae of severe brain injury. One group participated in a psychoeducational stress management program that emphasized instruction in coping skills and group discussions of coping efforts. The program included regular homework assignments, practice exercises, and follow-up discussions of the use of skills. The second group was an informational support group. Parents identified topics that they wanted to discuss and were also encouraged to share their feelings with group members. The impact of the two groups was measured with standardized self-report measures of depression and anxiety. Parents in the stress management group experienced significant reductions in depressive and anxious symptoms. Parents in the informational and sharing group, as a group, showed increases in depressive and anxious symptoms. *Key words: acquired brain injury, coping skills, psychosocial interventions, stress management*

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**A** CHILD WHO experiences a severe acquired brain injury (ABI) is in many ways forever changed and continually challenged. But it is not only the child who is changed and challenged—the family who loves that child is often also devastated. Initially, the injury itself and the accompanying hospitalization involve severe emotional and instrumental stresses as the family deals with the frightening uncertainty of their child's survival. In addition to these events that surround the injury, severe brain injury usually results in long-term sequelae, which can challenge a family's coping resources. Of particular difficulty for families are the emotional and behavioral problems of their family member with ABI.<sup>1-3</sup> As these problems tend to endure and, in some cases, worsen with time,

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families continue to experience stress in coping with these changes over the long term.<sup>2,3</sup> Furthermore, parents of children with severe ABI must undergo a process of gradually realizing the ways in which their child is permanently changed from the premorbid condition.<sup>4</sup> This process of accommodation to a changed child often involves strong grief reactions, including feelings of loss, intense sorrow, and a questioning of basic cognitive assumptions.<sup>5</sup>

For children with severe brain injury, the need for support services does not diminish with time. Consequently, parents must make accommodations that can be sustained over the long term. Parents must accommodate to a changed child and, at the same time, continue their other roles as spouse, parent of the injured child's siblings, worker, and homemaker. As a parent said in one of our support groups: "It isn't enough to just do battle for a child's life. Then comes the battle to get rid of machines, the battle with insurance companies, the battle for services, the battle for information, the battle of holding yourself together with a spouse and other children, and there seems to be no end." Several important family functions can be adversely impacted by ABI in a family member.<sup>6</sup> Disruptions affect the emotional as well as instrumental roles that typify normal family life.

Authors have noted the need for counseling to assist parents of children with ABI.<sup>7,8</sup> Psychosocial interventions have been recommended to both alleviate parental distress and to facilitate rehabilitation efforts. Rutter<sup>9</sup> found that adverse family situations increased the likelihood of psychiatric disturbance in children with brain injuries.<sup>1</sup> By contrast, families that adapt successfully are more likely to facilitate long-term rehabilitation. Little empirical guidance is available to assist practitioners in choosing treatment methods for parents of children with ABI. Parent

and rehabilitation programs, but no research has yet examined what kind of content and group process is likely to help parents with their emotional distress. Sachs<sup>10</sup> suggested that psychosocial interventions for families of survivors of brain injury may rightfully have at least four different purposes:

1. to educate parents about the impact of head injury and the process of rehabilitation,
2. to teach coping skills and resolve practical problems,
3. to allow parents to express feelings and garner social support, and
4. to resolve emotional and structural problems in the family.

The purpose of this study was to compare two forms of parent support groups: an *informational and emotional support group*, which aimed to answer parents' questions about ABI, while providing a group milieu that encouraged emotional expression, and a *stress management group*, which aimed to improve coping, provide social support, and reduce psychological distress associated with caregiver stress. There is precedent for both approaches in the literature on support for family caregivers.

Support groups are a common vehicle for providing these different forms of assistance. While, to date, there have been no published studies comparing treatment approaches for parents of children with ABI, there have been related studies in the broader literature on caregivers of persons with chronic illnesses.<sup>11</sup> Two commonly reported approaches are informational groups and psychoeducational support groups. Informational groups aim primarily to disseminate information about illness, treatment, and resources in a supportive social context. Psychoeducational groups aim to impart skills that are thought to be useful for caregivers and to generate social support between members of the group. In the litera-

ness and disability, researchers have begun to compare these approaches.<sup>11</sup> For example, Lovett and Gallagher<sup>12</sup> compared three groups of adults who were caring for frail elderly relatives. Subjects were assigned to one of three conditions: a wait-list control group, a psychoeducational group that focused on self-change skills aimed at improving life satisfaction, and a problem-solving group. Both of the treatment groups showed significant reductions in depression and improvements in morale compared to the wait-list group. There were no significant differences between the two treatment groups. Ingersoll-Dayton et al<sup>13</sup> compared two approaches to serving caregivers of persons with disabilities and chronic illness. They provided a 7-week educational seminar to all subjects and then allowed them to choose between a care planning group, a social support group, and the buddy system. Subjects in the care planning and support groups showed significant reductions in negative affect; however, interpretation of the comparisons is hindered by the lack of random assignment.

Researchers have gathered a considerable body of empirical evidence about coping skills used to help people accommodate to a variety of stressful circumstances.<sup>14-16</sup> These stress management approaches to treatment focus on providing caregivers with cognitive and behavioral skills that can be used during normal daily activities. For example, they often include instruction in how to identify signs of stress and how to perform brief relaxation exercises in difficult circumstances. Other more cognitive approaches help people to prepare for difficult situations by rehearsing protective ways of thinking and coaching oneself in response to stress. Recently, researchers have tested the efficacy of these techniques with parents of children with severe handicaps.<sup>17,18</sup> These studies have found that parents who participate in a stress management program experience sig-

nificant reductions in levels of depressive symptoms and anxiety. The parents in these studies had children who were born with severe disabilities. The purpose of the research reported here was to test whether similar stress management procedures could be effective in helping parents of children with ABI and to compare stress management training with another common approach to supporting parents through informational meetings.

## METHOD

### Subjects

Parents were recruited from a rehabilitation program for children with ABI in a small city in the Pacific Northwest. Fifteen parents participated in the study. They were parents of nine individuals with severe disabilities as the result of ABI. Five marital dyads participated; consequently there were fewer children than parents because members of these five dyads shared the role of parenting the same child. Tables 1 and 2 present demographic data on the two groups of parents. There were no significant differences between the groups with regard to size of family, years of education, socioeconomic status, or age of the child at the time of injury. Characteristics of the children with ABI are presented in Tables 3 and 4. The length of coma for the children ranged from less than a day to 42 days. The length of time since the injury occurred ranged from 3 months to 66 months with a mean of 23 months. All children had enduring sequelae and required long-term rehabilitation and special education services.

### Measures

In order to measure depressive symptoms, we used the Beck Depression Inventory (BDI).<sup>19</sup> The BDI is a self-report measure of symptoms and attitudes that are thought to be characteristic of depression (eg, pessimism,



Table 1. Descriptive information for families in stress management group (n = 7)

Sex*	Marital status <sup>†</sup>	No. of others in home	Education (in years)	Age of injured child
M	M	3	12+	13 y
F	M	3	12+	13 y
M	M	0	16	20 y
F	M	0	16	20 y
M	D	0	12+	21 mo
F	D	0	12+	21 mo
F	M	3	16	20 y

\*M = male, F = female

<sup>†</sup>M = married; D = divorced

self-dislike, and fatigue) The BDI has been widely used to measure stress reactions in general.<sup>20</sup> In over 25 years of research, it has exhibited acceptable psychometric properties, including internal consistency and stability, as well as evidence of construct validity.<sup>21</sup>

The State Scale of the State-Trait Anxiety Inventory (STAI) was used to measure anxiety.<sup>22</sup> The STAI-State Scale is a self-report measure of anxiety that is presently experienced as a temporary state. The scale has high reported internal consistency, and evidence for discriminate and convergent validity has also

been provided.<sup>22</sup> The STAI has also been widely used in stress research.<sup>20</sup>

#### Procedure

Parents of children who had been inpatients in a pediatric rehabilitation hospital in the Pacific Northwest were informed of the availability of support groups. After obtaining informed consent, parents were randomly assigned to one of two groups: information and stress management. Seven parents were randomly assigned to the stress management class and eight to the information comparison

Table 2. Descriptive information for families in information/support group (n = 8)

Sex*	Marital status <sup>†</sup>	No. of others in home	Education (in years)	Age of injured child
F	M	1	12+	7 y
F	M	1	12	5 y
M	M	1	8+	11 y
F	M	1	12+	11 y
F	M	0	16+	16 y
F	M	2	12+	20 y
M	M	0	12	20 y
F	M	2	16+	12 y

\*male, f = female

<sup>†</sup>marned, D) = divorced

Table 3. Descriptive information for children: stress management group

Sex*	Age	Cause of injury	Time since injury (in months)	Length of coma	Degree of disability	Nature of deficits
M	13 y	Sports accident hit by baseball	10	4 days	mild	Temper control, executive functioning
M	20 y	Bicycle/MVA <sup>†</sup>	66	12 mo.	severe	Quadriplegia, seizure disorder, severe dysarthria
M	21 mo.	MVA	3	0	severe	Quadraparesis, seizure disorder
M	20 y	MVA	44	35 days	severe	Expressive aphasia, hemiparesis, executive functioning

\* M = male

<sup>†</sup> MVA = motor vehicle accident

group. Couples were assigned in pairs; three couples were assigned to the stress management group and two to the information group.

Both groups were led by a PhD-level psychologist who had prior clinical experience leading groups, as well as considerable experience with pediatric brain injury. Both interventions consisted of nine 2-hour meetings that were held once a week at the hospital.

#### Stress management classes

The stress management classes were designed to combine two approaches to helping: psychoeducational instruction of coping skills and parent-to-parent self-help and social support. The leaders of the stress management classes followed a written manual (Hawkins NE, Powers L. Unpublished *Stress Management Manual*). In keeping with the psychoeducational approach, the group leader served as a coach and teacher. She demonstrated coping skills, assigned practice exercises in class and as homework, and pro-

vided feedback to members about their efforts to use the coping skills. The self-help and social support aspect of the class emphasized the creation of a positive social milieu in which parents were encouraged to share experiences, feelings, and coping methods with one another. The box entitled "Content of Stress Management/Support Group Classes" presents a list of the topics covered.

The classes were based on the assumption that coping skills can be modeled and learned through practice and reinforcement. In this orientation, difficulty in coping is seen as a sign of deficient environmental resources and/or skill deficits, rather than as a sign of pathology. Further, it is assumed that coping skills can be used to enhance quality of life as well as to alleviate distress. Thus, the approach can be used for promotion and prevention, as well as for amelioration, of distress.

Each class began with a short review of the previous week's topic and a discussion of parents' experiences in using the coping skills

during the past week. The leader answered questions and encouraged parents to share their experiences with one another. After reviewing homework, the leader presented a new coping skill, modeled it, and coached parents through role play practice. Parents were then assigned homework. Assignments included:

- keeping a daily log of stressful events and coping responses,
- practicing Progressive Muscle Relaxation (PMR) with an audiotape,
- practicing short forms of relaxation in stressful events,
- monitoring self-talk in stressful situations, and
- keeping track of helpful social contacts.

The assignments provided the focal point for each in-class discussion. Approximately half of each class was devoted to instruction and half to group discussion. Each class lasted

for 2 hours. Between class meetings, a secretary made weekly telephone calls to parents to answer questions about the homework.

#### Information and emotional support group

The focus of the information group was to provide parents with an understanding of the many issues surrounding ABI and to create an environment where parents could support one another in their efforts to deal with these issues. The primary differences between the stress management classes and the information classes was that the classes for the information group focused on discussions with a greater emphasis on issues concerning the children with ABI and the stress management classes focused on parent's adaptation and skills training. Session topics were determined by parents; they are listed in the box entitled "Parent-Generated Topics Discussed

Table 4. Descriptive information for children: information/support group

Sex*	Age (in yrs)	Cause of injury	Time since injury (in months)	Length of coma	Degree of disability	Nature of deficits
M	7	Seizure disorder	34	0	moderate	Lennox-Gastaut syndrome, epilepsy
M	5	Brain tumor	27	0	severe	Aphasia, seizure disorder, growth hormone impairment
M	11	Pedestrian/MVA <sup>†</sup>	9	21 days	severe	Left hemiparesis, aphasia
F	16	MVA	11	9 days	moderate	Temper control, executive functions, emotional lability
M	20	MVA	9	42 days	severe	Aphasia, blindness, executive functions, short-term memory

\* = male, F = female  
<sup>†</sup>A = motor vehicle accident

### Content of Stress Management/Support Group Classes

1. *Self-monitoring.* Participants were given a structured daily diary to indicate stressors, responses to stress, and coping responses. The content of the diary was used as a basis for group discussions and for planning specific coping strategies around discrete stressors.
2. *Progressive muscle relaxation (PMR) and visualization.* Participants were guided through a short form of PMR and given audiotapes to coach them through practice sessions at home. Subjects practiced relaxation and guided visualization during a portion of each class.
3. *Relaxation as an active coping skill.* Participants were taught to recognize internal cues of stress responses and coached to respond with short forms of relaxation.
4. *Cognitive coping with shattered assumptions.* One class was devoted to a guided discussion about the way that trauma can threaten basic beliefs about a just world and invulnerability. Parents were encouraged to share their attempts to give meaning to their child's condition.
5. *Cognitive coping with thoughts associated with stress reactions.* Parents were given daily diary forms to note depressive thoughts about stressors. They were coached to challenge these thoughts and substitute other ways of thinking.
6. *Social support as a buffer against and an aid in dealing with stress.* Participants were guided through a review of the kinds of social support available to them. They monitored social contacts with a daily diary and set goals concerning ways to increase certain kinds of social support.
7. *Modulating strong effect.* The group leader facilitated a discussion of grief reactions to sequelae of pediatric traumatic brain injury. Parents were given suggestions about allowing certain times and places for expressing strong emotion related to grief and loss.

in Information/Support Group." It shows that the meetings were devoted entirely to discussion of topics that the parents generated. They chose to focus on issues concerning the sequelae of ABI experienced by their children, as well as their own challenges. The discussions frequently served as an opportunity for parents to express strong emotions about the stresses involved in caring for their children. Unlike the stress management group, the information group did not provide skills training nor assign homework.

#### Data analysis

The design of the study was a two group, pretest-posttest experimental comparison using random assignment to each condition. Analyses of Covariance (ANCOVA) were used to analyze the data. The pretest scores on the BDI were used as a covariate of the posttest

BDI score, and the pretest scores on the STAI were used as a covariate of the STAI posttest scores.

#### Results

Table 5 presents the pretest, posttest, and adjusted means scores and standard deviations for the two groups on the BDI. It shows that the stress management group experienced reductions in depressive symptoms compared to the information-only group ( $F = 7.00$ ,  $df = 1$ ,  $P = .02$ ). The ANCOVA analysis revealed that the statistical assumption of homogeneity of variance was met. Table 6 presents the pretest, posttest, and adjusted means for the two groups of the STAI-State Scale. It shows that the stress management group experienced reductions in symptoms of anxiety compared to the information-only group ( $F = 4.8$ ,  $df = 1$ ,  $P = .04$ ).

**Parent-Generated Topics Discussed in Information/Support Group**

1. *Brain injury: the aftermath.* Parents elected to talk about the social and emotional sequelae of ABI pertaining to the injured child, parents, and siblings. The discussion included talk about how parents cope with their child's problem behaviors. They also talked about medical care as a source of stress. (2 sessions)
2. *Recovery.* The parents discussed feelings of fault and blame for the child's condition. They shared their sense of a loss of control following the injury and ways of regaining a sense of control. They also discussed feelings of burnout.
3. *Realistic outcomes.* This class generated group discussions of what parents could expect over the long term from their injured child and from their own feelings. It included a discussion of stages of grieving and ways to manage grief and stress. The importance of community support and other factors that affect outcome were also topics of discussion.
4. *Behavior management.* These discussion sessions centered on behavior problems in the children with ABI and their siblings. Parents described common behavior problems, and the group leader suggested ways of managing the problems. (3 sessions)
5. *Coping with the stress of brain injury.* This discussion centered on long-term sources of stress in caring for a child with ABI. The parents suggested ways of coping with stress such as attending support groups, exercising, taking time for oneself, etc.

**DISCUSSION**

It is clear that the parents of a child who experiences an ABI often experience psychosocial trauma themselves. With increasing numbers of children surviving major closed head injuries, there will be a growing and cumulative population of family caregivers.

They are likely to need psychological and social supports to assist with the long-term effort of caring for a child with ABI. The 15 parents in this study had a group mean score of 10.2 on the BDI, indicating a mild level of depression. By contrast, population studies with the BDI have found that the average score in persons who are not under unusual stress is

**Table 5.** Group comparison statistics for the Beck Depression Inventory (BDI)

Group	Pretests		Posttests		F
	Adj. mean	SD	Adj. mean	SD	
Stress management (n = 7)	15.0	9.73	7.71	6.80	7.07*
Information (n = 8)	10.13	6.81	13.88	10.84	



Table 6. Group comparison statistics for the State Scale of STAI

Group	Pretests		Posttests		F
	Adj. mean	SD	Adj. mean	SD	
Stress management (n = 7)	49.86	12.54	36.14	11.36	4.88*
Information (n = 8)	44.88	9.37	45.38	12.55	

\* $P < .05$ 

4.54 (SD = 4.46).<sup>23</sup> Elevated levels of depressive symptoms should be of concern to pediatric rehabilitation personnel for two reasons:

1. People with depressive symptoms have been found to have significantly poorer social functioning and role functioning than people without elevated depressive symptoms.
2. Elevated levels of depressive symptoms have been shown to interfere with normal parent-child interactions.<sup>24,25</sup>

Mothers with depressive symptoms, compared to women without symptoms, interact less with their young children, are less positive, use more explosive discipline, and are less contingently responsive.<sup>25</sup> Because many children with ABI require a consistent and highly structured social environment, the quality of parent-child interactions is an important component of rehabilitation. Given the importance of parental consistency for children with ABI and the elevated risk for depression in parents, practitioners need effective means to help parents in order to achieve child-focused rehabilitation goals.

As hospital, rehabilitation, and public school programs all serve this population of parents, it will be increasingly necessary to identify effective family support services. This study describes an initial effort to evalu-

ate a psychoeducational approach for assisting family members to cope with the emotional impact of pediatric ABI. The results suggest that a stress management program combined with a supportive group milieu can assist parents with their depressive symptoms and with state anxiety.

It is important to note some limitations of this study. First, the numbers of parents in each group were small. Secondly, the proper analysis of data involving family members is controversial. The statistical assumption of independence is violated when couples are assigned in pairs to groups, but observations are collected from individuals. We believe that we are justified in considering them as independent data points because our dependent measures were self-report measures of subjective states and our interventions did not focus on persons as members of a couple. That is, the educational discussions and the coping skills instruction were aimed at individuals, not the couples as a group. Nonetheless, MANCOVA analyses, as with all inferential statistics, rely on the assumption that data points represent independent observations. In addition, it is possible that the unequal numbers of couples in the two groups accounted for some of clinical gains in the stress management group, which had more couples

than the information group. That is, it is possible that there is an additive effect when members of couples participate together. Given these concerns about statistical validity, this study should be regarded as an exploratory investigation, and the results should be interpreted modestly as a possible spur to more research. Further research is warranted in order to verify the claim of efficacy. At the same time, we would point out that, clinically, it was clear to the group leaders that the stress management group appeared to improve in morale and the information group did not. Also, all but one member of the stress management group had a reduction in self-reported depressive symptoms. The one who did not started with a low score, indicating few symptoms, and stayed at the same level. By contrast, four members of the information group showed increased symptom levels, one did not change, and two showed small improvements.

A further limitation of this study should be noted. Because we were primarily interested in measuring the impact of the two treatment approaches on parental depression and anxiety, we did not include measures such as knowledge about ABI or perceived social support. Had these measures been included, it is possible that the information and emotional support group would have also shown positive outcomes but in different domains, although such findings would be clouded by the increase in parental distress experienced by half of the information group members. Thus, the study should not be interpreted to mean that informational and emotional support groups are completely ineffective; rather, it suggested that skills training is likely to be necessary to effect changes in distress due to the day-to-day stress of adjusting to ABI in the family. It is unlikely that parents will learn coping skills unless those skills are specifically targeted and taught. Similarly, it could not be assumed that a class that fo-

cuses on parental coping skills will necessarily communicate new information about brain injury, although our clinical experience suggests that parents do in fact share considerable information in an informal and unstructured manner.

Our clinical observations suggest that, at least among the group of parents in this study, one important feature of the stress management group was its focus on positive adaptation. The emphasis on skill building allowed parents to experience success in dealing with specific stressors. Reporting these accomplishments helped to establish a norm in the group that difficulties can be at least partially ameliorated. This stress management group also appeared to establish a group consensus that it was acceptable for parents to devote time and energy to taking care of themselves. The parents who were involved in the study had all been intensively engaged in efforts to assist their children through hospitalization and rehabilitation. Most of them appeared to be giving priority to their children over their own needs for rest and emotional support. Thus, the fact that the group was a time for the parents and that the coping skills home practice encouraged parents to take at least a few minutes each day to focus on their own needs appeared to be important in reducing depressive and anxious symptoms. By contrast, the information and emotional support group focused more on discussions about child-centered concerns such as the sequelae of ABI, the service system, and long-term planning. The emotional sharing often involved strong expressions of grief without many examples of positive coping efforts. While this emotional venting may have been useful to parents, it may actually have increased their emotional distress in the short term.

The combination of psychoeducational instruction and parent-to-parent social support holds promise as one component of a com-

prehensive family support system for families of children with ABI. The choice of cognitive and behavioral coping strategies for this class stemmed from our clinical experience with families of children with ABI, which has suggested that parents require support in learning to take care of themselves since the caregiving demands of ABI can so often overshadow self-care. Further, our experience had led us to believe that many parents experience intensive emotional responses to TBI and its sequelae and that it is important for parents to hear of successful efforts to cope with these reactions. We found that a class format that encouraged parents to talk about practical everyday stressors, as well as emotional responses to their child, helped to create a group process marked by a high level of emotional disclosure and interpersonal support in a milieu that suggested that parents could realistically hope to manage some of the stress in their lives. We believe that this parent-to-parent social support with an emphasis on active coping set a tone of hopefulness that was a critical component of the intervention. At the same time, the psycho-educational support strategies appeared to give parents practical skills which were useful in home and community settings. Because the emphasis in the stress management class

was on parental stress and coping, it was possible to work with a group of parents whose children differed greatly in regard to the etiology of their ABI, the age of the child, and the nature of the sequelae. It was not necessary to form groups around child characteristics because the focus was on parental stress and coping, which we believe to be similar regardless of the specifics of a child's injury history.

The field of pediatric rehabilitation for ABI is in a nascent state. As new support programs are developed, creative approaches to addressing the complex needs of families must be included. However, empirical data regarding the relative effectiveness of different approaches to supporting families are still lacking. It is important that future research examine a variety of approaches to helping families of children with ABI since every family reacts to and copes with ABI in their own unique way.<sup>26,27</sup> That is, the specific needs of parents must be matched to specific interventions. By tailoring interventions to parents' specific needs and by conducting controlled studies that allow us to assess which programs are most effective for particular purposes, we will progress in meaningful ways toward the goal of supporting families of children with ABI.

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**Comprehensive Family Support for Behavioral Change  
in Children with Traumatic Brain Injury**

Running Head: Family Support

Comprehensive Family Support for Behavioral Change in Children  
with Traumatic Brain Injury

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Comprehensive Family Support for Behavioral Change in Children  
with Traumatic Brain Injury

This chapter describes a comprehensive approach to intervention and support with families of children experiencing traumatic brain injury and behavior problems. The goals of the approach are to improve the behavior and lifestyle of the child with traumatic brain injury, to empower family members to effectively reintegrate the child into family life, and to help the family regain the cohesion and stability that are often shaken or lost after such an injury to a family member. The chapter describes the need for child and family-centered intervention approaches, discusses the theoretical basis and key features of one particular approach, summarizes the steps in the support process, and presents a case study of one family's effort to support an 11-year old boy experiencing traumatic brain injury and severe behavior problems.

The Need For Child And Family Centered Approaches

A traumatic brain injury to a child traumatizes the whole family (Pieper & Singer, 1991; Williams & Kay, 1991). In one survey, 80% of the parents of children with traumatic brain injury (TBI) reported symptoms that met the DSM-III-R criteria for Post-Traumatic Stress Disorder which is a disorder experienced by war veterans and survivors of catastrophic events (Nixon, 1992). Just as children who have survived TBI experience lifelong alterations, the families of these children also experience changes in the pattern of their daily lives, in their roles and care giving responsibilities, and in their expectations and hopes for the future. Children often experience deficits in cognitive abilities such as memory, organizing, planning, decision-making and problem-solving. Children who were formerly well behaved, well-liked by peers,

and successful in school may engage in behaviors that disrupt family life, friendships, and schooling. The confusion, grief, and disruption associated with these changes can overwhelm families. Family members may have difficulty maintaining or recreating the structure, order, and predictability that characterized their lives together before the injury. As they proceed through the rehabilitation process, both children with TBI and their families experience the falling away of family and friends and the dwindling of their social support (Livingston, Brooks, & Bond, 1985; Williams & Kay, 1991). This loss of social support may make the family's effort to regain stability and hope even more arduous. Clearly, the effects of the child's brain injury ripple through the structure and experience of the family.

The child's and the family's experience both parallel and interact with one another. For example, many children with TBI have behavior problems such as inappropriate social behaviors, aggression, and destructive tantrums. Such problems may begin as child-centered difficulties directly related to the brain injury, but the problem behaviors then come to affect the family system. The family's reactions to the child's behavior can affect whether these behaviors are maintained or changed (Dadds, 1995; Florian & Katz, 1991; Patterson, 1982). If a child's behavior is going to change, both the child and the family must change. Effective interventions therefore must be both child-centered and family-centered. This notion that the rehabilitation of the child and the family are inseparable is becoming more predominant in the special education field (Turnbull & Turnbull, 1991a) and in the TBI rehabilitation field (McKinlay & Hickox, 1988).

Despite these conceptual developments, there remains very little intervention research with families of children with TBI. Although behavioral intervention in residential rehabilitation facilities has been shown to effectively reduce behavior problems and rebuild adaptive skills among adults with TBI (Burke, Wesolowski, & Lane, 1988; Davis, Turner, Rolider, & Cartwright, 1994; Peters, Gluck, & McCormick, 1992), to date, no comprehensive intervention approach has been developed and shown to be effective with children with TBI and their families. In the family intervention literature, a family network strategy has been anecdotally reported to be helpful to families of children with TBI, but no data were gathered (Rogers, 1984). The family systems approach has been discussed in terms of its application to families and children with TBI (Turnbull & Turnbull, 1991a), but as yet there have been no attempts to empirically validate this approach with families of children with TBI. A definite need thus exists for the development and evaluation of comprehensive approaches to intervention aimed at addressing the challenges faced by children with TBI and their families.

#### Theoretical Basis And Key Features Of Approach

The comprehensive approach to intervention with families of children with TBI adopted here is drawn from current best practice in behavioral support to persons with disabilities and behavior problems (Carr, et al., 1994; Horner, et al., 1990; Meyer & Evans, 1989; Wacker & Steege, 1993), behavioral parent training (O'Dell, 1985; Patterson, Reid, & Dishion, 1992; Sanders & Dadds, 1993) and ecological approaches to family assessment and support (Bernheimer, Gallimore, & Weisner, 1990; Singer & Powers, 1993). Five key features characterize the approach: (a) a theory-guided understanding of child behavior problems and

family ecology; (b) the design of multicomponent, positive behavioral support plans; (c) a "goodness-of-fit" between the support plan and family ecology; (d) a focus on building successful family routines; and (e) the development of collaborative partnerships. These features are each discussed below.

Theory-guided Understanding of Child Behavior and Family Ecology. A central message in the literature on behavioral assessment and intervention is the importance of understanding the reasons for behavior problems, and the ecology in which behavioral support will be implemented. This information is essential for the design of effective, acceptable, and feasible behavioral interventions (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Horner, 1994). Applied behavior analysis research and social learning theory (Patterson, 1982; Wacker, Cooper, Peck, Derby, & Berg, in press) indicate that child behavior problems serve a clear purpose or function, and that behavior problems are developed and maintained within the moment-by-moment interactions between the child and parent. For example, a child with TBI who has become impulsive may demand that his mother bake cookies for him just before bedtime. If his mother refuses and her son whines and hits her, she may relent and bake the cookies. The child might then stop his aggression, and even help with baking. Although the mother may initially submit out of a sense of compassion for a son who has experienced so much trauma, her response also teaches an unintended lesson. That is, the child learns that aggression is an effective way to get what he wants when he wants it. The mother also learns something dysfunctional; that giving in to her son's unreasonable demands avoids or terminates aggressive behavior. These coercive processes, once embedded in family interaction patterns, may be difficult to change without

systematic intervention (Patterson, et al., 1992). Via functional assessment of the child's behavior problems, the purposes of the child's behavior can be understood, and the consequences that maintain behavior problems and ineffective parenting strategies can be revealed. This knowledge then informs the design of child-centered interventions that will render behavior problems ineffective at achieving their purposes, and that will rebuild family members' ability to effectively parent the child.

Ecocultural theory (Gallimore, Weisner, Bernheimer, Guthrie, and Nihara, 1993; Gallimore, Goldenberg, & Weisner, 1993) is a theory of child development in the family derived from cross-cultural ethnographic studies of family life (Whiting & Edwards, 1988). It provides a useful framework for understanding ecological influences on child development in the home and for designing interventions that are individualized to the family. The theory supposes that families socially construct child activity settings (i.e., daily routines) to accommodate the needs of their children within the constraints and opportunities present in the family's environment. Gallimore and colleagues (see also Bernheimer, et al., 1990) argue that daily routines are the appropriate unit of analysis for understanding the ecology of a family and for designing family-centered interventions because ecological influences on the family are present and can be observed to operate in each family routine. According to ecocultural theory, daily routines comprise several elements: (1) time and place; (2) persons present; (3) material resources; (4) goals, values, and beliefs about child raising and family life; (5) tasks and how they are organized; (6) motives and feelings; and (7) common scripts or patterns of interaction. Families proactively strive to construct routines that are meaningful given their values, congruent with their children's

characteristics, and sustainable over time. The construct and concurrent validities of ecocultural theory were recently demonstrated by Nihira, Weisner, and Bernheimer (1994) in a longitudinal study of 102 families of children with developmental delays.

During assessment with families of children with TBI, an analysis of daily routines is particularly useful. When families discuss their efforts to parent their child with TBI, it is not uncommon for them to describe their successes or difficulties in rousing the child for school in the morning, orchestrating a pleasant dinner together, or helping the child prepare for bed. For many families of children with TBI, routines that once worked reasonably smoothly are now fraught with obstacles and problems, not the least of which are behavior problems. As the family describes the elements (e.g., goals, tasks, resources) of routines, many layers of the family's ecology are revealed, including family values, structure, functions, and interaction patterns. Viewing the daily routine as a microcosm of family ecology can lead in several ways to the design of individualized and effective family interventions. First, it suggests that interventionists should view the unit of analysis and intervention as the family routine, as opposed to focusing solely on behavior problems and parenting skills. Second, it encourages interventionists to design child- and family-centered interventions that are effectively embedded in family routines. Lastly, if interventions support the success of valued routines, they are more likely to be accepted and implemented by the family.

Design of Multicomponent Positive Behavior Support Plans. The technology of positive behavioral support, that has emerged largely from work with persons with severe disabilities, has much to offer children and families experiencing TBI. The approach emphasizes the design of



individualized, multicomponent behavioral support plans. These plans are logically linked to functional assessment data, and serve not only to ameliorate behavior problems but also to promote lifestyle improvement (Horner, et al., 1990). Interventions are drawn from a growing body of empirically verified ecological/lifestyle, antecedent/proactive, educative, and consequent interventions, with an emphasis on prevention and education. Support plans are designed collaboratively with family members, educators, and other consumers of the support plan, and only those interventions judged to be acceptable and likely to be effective are included in the plan (Sprague & Horner, 1991). Positive behavioral interventions verified through applied research include improving activity patterns (Malette, et al., 1992), offering choices (Dunlap, et al., 1994), providing information to increase predictability (Flannery & Horner, 1994), teaching communication skills to replace behavior problems (Carr, et al., 1994), teaching self-management skills (Kern Koegel, Koegel, Hurley, & Frea, 1992), and embedding preferred tasks within non-preferred tasks (Horner, Day, Sprague, O'Brien, & Tuesday Heathfield, 1991).

Two critical features of positive behavioral support, a focus on life style change and the importance of multicomponent intervention plans are particularly relevant to the needs of children with TBI. Children with TBI often experience dramatic setbacks in their lifestyle. A child may no longer be able to participate in favorite activities requiring abilities that have been compromised due to the injury (e.g., sports). Friendships may be lost and difficult to reestablish. Conversation with family members may be harder to start or maintain. This loss of valued experiences can alone be a source of behavior problems. Lifestyle interventions that emphasize

the rebuilding of valued activities and social relationships may help to ameliorate behavior problems.

Children with TBI also experience behavior problems for a variety of reasons that are unlikely to be adequately addressed by only one or two behavioral interventions. In addition to lifestyle deficits, children with TBI may experience impairments of bodily function, loss of impulse control and social skills, frustration with communication and academic performance, and interactions that may inadvertently reinforce behavior problems. Also, for any particular child with TBI, behavior problems may serve different purposes such as attention-getting, avoidance of aversive tasks, or protestation of a lost ability or opportunity. A comprehensive behavior support plan must address all of the relevant conditions that trigger or maintain behavior problems, and each of the purposes of the child's behavior (Horner, O'Neill, & Flannery, 1993). For example, a child with TBI may cry and scream uncontrollably whenever she sees other children playing sports activities. This event may painfully remind her that since her injury, she no longer participates in swim meets or gymnastics. She may also scream when her father talks with her brother but does not include her in the conversation. Though the behavior problems are the same in each example, the purposes of the behavior are quite different. In the former, the child screams to protest a lost opportunity; in the latter, she screams to get attention. Interventions need to address each separate purpose directly if the family hopes to reduce screaming. Potential interventions logically linked to the functions of screaming might include creating opportunities to participate in sport activities geared toward her more limited abilities, and teaching her to ask for attention and participate in conversation. Because behavior problems

often serve multiple purposes, support plans will necessarily require multicomponent interventions.

"Goodness-of-Fit" with Family Ecology. The effectiveness of a well designed positive behavioral support plan depends on the extent to which interventions are in fact carried out. Effectiveness can also be judged by the degree to which interventions are implemented and maintained across all of the relevant settings in which behavior problems occur. Recently, behavior analysts and family interventionists have suggested that behavioral support plans are more likely to be implemented with fidelity and maintain over time if they fit well with the ecology of the family (Albin, Lucyshyn, Horner & Flannery, in press). Family variables relevant to "goodness-of-fit" include family goals, strengths, available formal and informal resources, and sources of stress. Behavioral interventions that fail to address family goals, that ignore family strengths, or that add significant stress will not be implemented or sustained. For example, a parent may desire to eliminate behavior problems and to receive more help from other family members. If the support plan includes interventions aimed only at reducing behavior problems but provides no means to strengthen informal supports in the home, the plan may fail due to parental exhaustion or resentment. Interventionists need to listen to families and learn about their goals, strengths, resources, and stressors. They then need to collaborate with families and other stakeholders in the child's life (e.g., teacher, physical therapist) to design interventions that are not only technically accurate but also contextually appropriate and feasible (Horner, 1994).

Building Successful Family Routines. A common subjective experience of families of children with TBI is to feel overwhelmed by the changes in their child and in their family's life.

A multicomponent support plan should be designed to ameliorate, not add to, these feelings of helplessness. One strategy to make comprehensive support feel "doable" to the family is to implement interventions in one routine at a time. Doing so may make the plan appear more feasible, and thus strengthen the family's perception that the plan will work. Intervening on the level of the routine may help the family cognitively reframe the challenges they face in supporting their child's rehabilitation (Turnbull, et al., 1993). Rather than facing an insurmountable crisis, the family may see that they face the more manageable task of improving routines that are no longer working.

Another benefit of tailoring interventions to fit family routines relates to the family's interpretation of a stressor such as a pediatric head injury. The impact of a stressor is mediated by an individual's interpretation of it (Lazarus & Folkman, 1984). Therefore, the impact of a child's brain injury on the family is affected by the perception of stress by the family (Chwalisz, 1992). One family may find the personality change of their child to be the greatest stressor, while another family may experience the loss of social support as the most stressful outcome. The brain injury to a child should be understood in terms of the subjective experience of the family, and interventions should be tailored to that subjective experience. For example, interventions designed to improve a bedtime routine in which one parent is stressed by exhaustion and feelings of isolation are likely to include skilled respite care at other times of the day, and a weekly schedule of help during the routine negotiated with other family members.

The importance of routines to family coping is supported by research on everyday stressors and hassles (Kanner, Coyne, Schaeffer, & Lazarus, 1981). Some researchers have found daily

hassles (e.g. disruptions in daily routines) to be a better predictor of family stress and coping than major life events (DeLongis, Coyne, Dakof, and Folkman, 1982). The implication of this finding for interventions with children with TBI and their families is clear: The impact of the brain injury on a family is, to an extent, mediated by disruptions in daily routines. It follows then that the negative effect of the brain injury on the child and the family can be ameliorated by making family routines more effective and 'hassle-free'.

A final advantage in intervening at the level of the routine is that generalization and maintenance of treatment effects may be more likely because behavioral interventions are embedded within the ecology of routines (e.g., goals and values, tasks, resources) (Albin, et al, in press; O'Donnell & Tharp, 1990). Families who succeed in promoting behavioral change in two or three routines may find it easier to apply interventions in other routines that share similar properties. For instance, if a mother successfully motivates her son to go to bed cooperatively by reviewing behavioral expectations and negotiating a reward natural to the routine (e.g., reading a story to him after completing the routine) she may use similar practices to motivate him to behave properly at the dinner table. Also, behavioral improvement may endure over a long period of time because the interventions were specifically tailored to fit the ecology of the routine, including the social supports necessary for maintenance. For instance, if both parents equally shared the task of supporting their son in the bedtime routine, both parents may get the rest they need to continue using the support plan.

Building Collaborative Partnerships. The values and practices in the family support approach are designed to empower family members and to build strong collaborative relationships between

the consultant, the family, and the other team members (Dunst, Trivette, Gordon, & Starnes, 1993). Family knowledge is respected and collaboration with the consultant and other team members is encouraged throughout assessment and intervention. Families of children with TBI are the ultimate experts on their child's strengths and behavior problems, and on their family's ecology. Although the family may feel overwhelmed as a result of the trauma to their child and the disruption to their lives, they still possess many strengths and resources that can contribute to the success of a support plan.

It is therefore essential that family members collaborate in the design and selection of behavioral interventions, in the selection of routines in which to intervene, and in the choice of implementation support activities. Family members also should evaluate the acceptability and effectiveness of plan goals, interventions, and outcomes, and recommend revisions in interventions or support activities that are not working well. The consultant should encourage collaborative relationships between the family and key stakeholders such as the child's teacher or skilled respite care providers via team meetings, coordination of implementation across home and school, and development of formal supports to the family (e.g., skilled respite care). These values and practices contribute to the development of a strong therapeutic alliance between the family and the consultant (Kanfer & Grimm, 1980) and to the development of a community of support around the child and the family. Such an alliance and community can help to overcome the trauma of TBI and help to rebuild the child's and the family's life together.



### Steps in the Comprehensive Family Support Process

The key features of the support approach have been organized into a seven step behavioral consultation process: (1) referral, (2) comprehensive assessment, (3) preliminary plan design, (4) team meetings and plan finalization, (5) implementation support, (6) continuous evaluation and plan revision, and (7) follow-up support. The process, described in detail by Lucyshyn and Albin (1993) is briefly summarized below with emphasis on the way in which each step in the process is relevant to children with TBI and their families.

Referral. The referral interview has several purposes. First, during the initial interview, the consultant assesses for extreme situations such as life-threatening behavior or suicidal tendencies. These kinds of situations require immediate action by the consultant. During the referral interview the consultant also obtains informed consent. The consultant informs family members of what will be involved in the development and implementation of a comprehensive family support plan, emphasizing that the plan will be developed cooperatively with the family.

Another purpose of the referral interview is to identify the stakeholders whose participation could contribute to improvement in the child's behavior and lifestyle. In addition to the child's parent(s), stakeholders may include siblings, friends, education professionals, and community service representatives (e.g., scouting, respite services). Potential stakeholders nominated by the family are invited to participate in assessment and plan design activities as members of a family support team.

The referral interview provides an occasion to reframe the family's problems in a more positive light. The consultant stresses that as the child's family, they possess most of the information needed to design a support plan, that the support effort will be guided by their values, and that the plan will build on their strengths. The consultant also notes that intervention will occur in the context of family routines, and that the family will participate in the selection of routines, interventions, and support activities. Finally, the consultant also shares with the family success stories about prior interventions with other families similar to themselves. The goal of the reframing process is to help the parents believe that they are powerful, in control, and capable of effecting change.

Comprehensive Assessment. The synthesis of child and family-centered approaches to intervention is reflected in the second step of the support process. The assessment consists of a functional assessment of behavior problems and a family ecology assessment. The goal of the functional assessment is to provide information necessary for the design of an individualized behavioral support plan for the child. The goals of the family ecology assessment are to provide information necessary for the design of family-centered interventions, and for the creation of a "goodness-of-fit" between the behavioral support plan and the family's ecology.

The functional assessment uses the assessment protocol designed by O'Neill and associates (O'Neill, Horner, Albin, Storey, & Sprague, 1990). Information gathered during the assessment includes: (1) a specific description of behavior problems; (2) ecological factors associated with those problems (e.g., medical problems, activity patterns); (3) educational factors (e.g., skill

deficits in language); (4) common predictors (e.g., interruptions, difficult tasks, transitions); and (5) possible functions of the behaviors and their maintaining contingencies.

Assessment activities consist of interviews and observations in home, school, and other relevant settings as appropriate. In addition to family participants, interviews and observations typically include other team members such as the child's teacher or physical therapist. Interviews are casual, jargon-free, and respectful of the knowledge and expertise of each team member. The consultant also may ask parents or teachers to complete observations in the home or school using a functional analysis observation form (O'Neill, et al., 1990). From these interviews and observations, the consultant develops hypotheses about the functions of behavior problems and about the promotion of desirable behavior.

The family ecology assessment consists of two interviews. During the first interview, the family replies to open-ended questions about family goals, strengths, resources and social supports, and sources of stress (Turnbull & Turnbull, 1991b; Summers, Behr, & Turnbull, 1989). During a second interview the family describes the daily routines in which their child participates. After enumerating all current routines, the family identifies 3 or 4 routines in which they would like to intervene, and then describes what each routine would look like if it were successful.

In addition to gaining information necessary for the design of a comprehensive family support plan, the assessment process gives the family critical information about their child and family. When families conduct functional analysis observations, they discover the types of interactions or events that trigger behavior problems, and the purposes that the child's behaviors

serve. Behavior problems become cognitively reframed from willful acts of noncompliance to inappropriate attempts to satisfy important wants and needs. The family ecology assessment has a similar awareness-building function. For instance, when families talk about their strengths, they are reminded that despite the trauma of TBI, they still possess many qualities of an effective family: Both parents may recognize that they remain loving and forgiving in their relationship with their children; a mother may see that her ability to coordinate family activities remains intact; a father may realize that he continues to effectively support his children. Acknowledging strengths and resources helps families regain the sense of hope that may have been lost through grief and the struggle to cope.

Preliminary Plan Design. During and immediately after the comprehensive assessment the consultant engages the family and other team members in a dialogue about the content of a preliminary positive behavior support plan and implementation plan. Guided by the hypotheses generated during the functional assessment, they together discuss interventions that may render behavior problems irrelevant, ineffective, and inefficient in achieving their purpose. Five categories of intervention are considered: (1) ecological/lifestyle interventions; (2) antecedent/proactive interventions; (3) interventions to teach new behaviors or skills; (4) effective consequences; and (5) emergency procedures. Effective consequences typically include positive reinforcement strategies to strengthen adaptive behavior and de-escalation procedures to weaken behavior problems. Emergency procedures may be proposed if necessary to prevent physical injury or property destruction.

Information from the family ecology assessment is used to select child-centered and family-centered interventions that advance family goals, build on family strengths, use resources and social supports available to the family, and diminish sources of stress. For example, family goals may include helping their child with TBI make new friends, and finding ways for the parents to get more rest from care giving responsibilities. Interventions may include enrolling the child in the local chapter of Girl Scouts or developing a small group of skilled respite care providers. Information about family routines helps with the design of child-and family-centered interventions that are effectively embedded in the routines. For example, during a dinner routine an older sibling with an affectionate relationship with her brother with TBI may be willing to praise her brother for appropriate behavior during the meal.

The family and the consultant also discuss potential implementation support activities. The family and consultant collaboratively decide on the routines in which to intervene, and on the activities that will support implementation and long term maintenance. Potential activities include home meetings, behavioral rehearsal, and coaching in the actual routine. The result of this dialogue is a preliminary implementation plan that includes recommendations for support activities, roles, and timeline.

Team Meetings and Plan Finalization. The purposes of the team meeting are to finalize the behavioral support plan and implementation plan and to build collaborative relationships among team members. In preparation for the team meeting, the consultant summarizes functional assessment data and preliminary plans on flip charts. During the meeting, the consultant highlights the results of the assessment, reviews hypotheses, and guides a discussion of potential

behavioral interventions and implementation activities. During the review and discussion team member input is solicited. Plans are presented tentatively, and team members are encouraged to change, add, or delete any part(s). When disagreements arise, they are negotiated until there is consensus.

Effective team meetings achieve consensus on every level. Consensus about hypotheses, goals, interventions, and implementation activities will allow the finalized plans to be supported by all team members. Consensus also may strengthen collaborative relationships and commitment to improving the behavior and lifestyle of the child and family. Finally, consensus creates a context in which the family can be supported in the implementation of interventions, and in which responsibilities can be delegated and accomplishments acknowledged.

Implementation Support. During the implementation phase the family, the consultant, and other key stakeholders implement the behavioral support plan. Support activities defined in the implementation plan, such as behavioral rehearsal and home meetings are used to: (1) build or strengthen the family's capacity to support the child, (2) help enact lifestyle changes, and (3) sustain collaborative relationships. Most support activities take place in the family's home or neighborhood because this is where child and family problems occur. Changes in the behavior of a child with TBI can be made at a residential or rehabilitation facility, but these changes are unlikely to maintain when the child returns home if the reinforcement and interactional patterns of the family as a whole have not been changed (Willer & Corrigan, 1994).

When implementation begins, the consultant initiates support activities tentatively and flexibly. Some families may like a particular support activity (e.g., role play) while other



families find the same activity stressful. Thus, support activities need to be undertaken with flexibility until the right mix of effective and acceptable activities for a family is discovered.

Support activities commonly used during implementation support include: (1) written procedures that succinctly describe interventions and provide examples and non-examples of appropriate use; (2) implementation checklists that parents use to self-evaluate and self-monitor implementation fidelity; (3) behavioral rehearsal (role-play) in which parents and the consultant practice how to implement interventions; (4) coaching in the natural performance setting, involving instruction, modeling, and feedback; (5) home meetings where progress is reviewed, accomplishments acknowledged, and new or recurring problems solved; and (6) telephone consultation.

Continuous Evaluation and Plan Revision. Multiple methods of evaluation are used to assess the outcomes of the comprehensive family support effort. These methods are designed to answer four central questions: (1) Has the plan promoted meaningful and durable behavior change for the child; (2) has the plan improved the lifestyle of the child and family; (3) do parents and stakeholders use interventions effectively; and (4) do family members perceive plan goals, interventions, and outcomes as acceptable and effective?

Potential evaluation methods include direct observation, implementation checklists, social validity questionnaires, and qualitative interviews with key informants (e.g., parents, siblings, teacher). Methods of evaluation are selected during the team meeting and used continuously during implementation support. Information gained from evaluation data guide changes in implementation support activities, and revisions in child-centered and family-centered

interventions. When the data from multiple methods converge to indicate that the central aims of the support effort are being achieved, the consultant begins to fade his or her support, and the family and consultant confirm a date to terminate the consultant's regular participation in support activities.

Follow-up Support. Although interventions may prove effective and the support effort evaluated a success, the endurance of these positive changes cannot be assumed. For the child to continue his or her progress, the family will need to continue implementing interventions with fidelity, solve new problems as they arise, and respond deftly to life-cycle developments in the child and family. A variety of stressors are likely to impinge on the family, and may hinder family members' ongoing ability to support their child. Although behavior problems may have been reduced to near zero levels, they rarely disappear. The potential for regression is thus ever-present.

For these reasons, families often need follow-up support. At the conclusion of implementation support, families are encouraged to call the consultant when problems re-emerge or new issues arise. Sometimes these problems can be resolved through a series of phone consultations. Other times a home meeting may be required. In some cases where skills have eroded or interventions have been neglected, a series of coaching sessions in the home may be necessary.

#### Case Study

Michael was 11 years old at the time of the study. He lived at home with his mother and father, Peggy and Alan, and four siblings: Two older sisters, 14 and 17 years of age; and 2

younger brothers, 5 and 8. The family lived in a four bedroom house in a middle class neighborhood in a pacific northwest community of approximately 100,000. Both parents worked outside of the home.

Michael was 8 years old when he ran across a street and was hit by a car. In the accident, Michael suffered a severe brain injury with brainstem contusion and was comatose for approximately 4 months. Michael's initial hospitalization was agonizing for his family because they did not know if he would come out of the coma, or whether he would live or die. His parents described the experience as "unreal." They believed that when he awoke, Michael would be himself again. They reported that after he awoke and they realized his loss of ability, they experienced a shock from which they had not yet recovered.

After 4 months, Michael was transferred to a rehabilitation unit where he remained for 3 months before coming home. During those 7 months in the hospital, Peggy devoted almost all of her time to Michael at the hospital and was not available for the other four children. Only one of the siblings, his 14 year old sister, visited him at the hospital.

Outpatient rehabilitation occurred for two months, and then the family moved to another state where rehabilitation continued. The parents reported that immediately following the accident the family received much social support from their friends at church, but the subsequent move separated them from their social support network. The family had difficulty building a new social network in their new community, and at the time of the study Michael didn't have any friends.

Prior to the accident Michael had been in a talented and gifted educational program, performing at a grade and a half above his age level. Neuropsychological testing approximately one year post-injury revealed a significant visual-spatial deficit, poor fine motor control, and slow and dysarthric speech. He scored in the low-average range on a measure of intelligence and two to three grade levels below his expected grade level on academic measures. As a result of this loss of ability, Michael was placed in a self-contained special education classroom in his neighborhood school.

Michael's parents reported that before the accident he was a star athlete and soccer player. At the time of the study, the right side of his body was weak, the right side of his face drooped, and his right hand shook. Because of the weakness in his right leg, he walked with a limp, was very unsteady, and often fell down. He used his left hand to feed and dress himself. He wasn't able to write with his left hand and so wrote using a computer and keyboard.

Michael's personality and behavior also changed after the accident. He developed a temper that was much more difficult for him or others to control. He screamed, hit, bit, and threw things in flashes of intense anger not in that degree before the accident. Once he escalated into high intensity behavior problems, it was difficult for him to regain his composure. Like many children with TBI, he also lost many of his social skills. He asked strangers inappropriate questions, said whatever popped into his mind no matter how inappropriate, and acted immaturely in interactions with his peers.

### Referral

At the time of referral, Michael's family was desperate about their inability to control his angry outbursts and destructive behavior. They had seriously considered placing Michael in an inpatient program for children with TBI at a cost of \$20,000 per month. Michael's mother had participated in several support programs (stress and behavior management classes, a parent support group) for families of children with TBI, but her participation was episodic, and the services were not intensive enough to overcome Michael's behavior problems and related family problems.

Peggy learned about the availability of the comprehensive family support process during individual counseling at a counseling center that served families of children with disabilities. During the referral interview the family counselor described the comprehensive family support process, and emphasized the home-based and collaborative features of the approach. Peggy expressed a strong interest in participating while her husband Alan, though skeptical about the chances for success, was willing to try. The family consented to participate for a nominal fee, and also agreed to take part in research activities to evaluate child and family outcomes.

### Comprehensive Assessment

Functional Assessment. The consultant completed functional assessment activities with Michael's parents, his elementary school teacher, his sisters, and a volunteer respite care provider who had established a positive relationship with Michael. Assessment activities included functional analysis interviews, functional analysis observations in the home and school, and discussions about the purposes of behavior problems and about interventions that might

strengthen desirable behavior or diminish behavior problems. Assessment activities were completed across a 5 week period and required approximately 15 hours.

The functional assessment indicated that Michael primarily engaged in behavior problems in the home or community in the presence of family members. At school, Michael was in a highly structured program that included many functional and preferred activities, and the teacher was highly skilled in curriculum design and behavior management. Michael engaged in three types of behavior problems: (1) aggressive behaviors including slapping, hitting, kicking, and throwing things; (2) property destruction such as knocking objects off tables, and ripping clothing and furniture; and (3) whining and screaming. These behaviors sometimes occurred in an escalating sequence beginning with whining and screaming and ending with aggression or property destruction.

In the home several ecological conditions appeared to set the stage for behavior problems. Michael spent much time with his mother after school, and had few opportunities to leave the house and visit friends or engage in favorite sport activities. His mother often felt exhausted from her job, taking care of a large family, and being the primary care provider for Michael. Michael's father sometimes engaged in rough house play with the boys, including Michael, which involved playful slapping and punching. Siblings often avoided him because of fear of being slapped or hit. Several features of home routines appeared to provoke behavior problems including competition among brothers at the dinner time, difficult tasks during homework, unstructured leisure time in the middle evening, and an early bedtime next to a noisy family room.



Many of Michael's skill deficits were associated with his behavior problems. He had difficulty remembering social rules and controlling feelings of embarrassment, frustration or anger. His memory and communication deficits made it harder for him to ask for help or negotiate compromises. He also had difficulty structuring free time and remembering scheduled events. Finally his loss of motor skills seriously limited his opportunities to participate in previously enjoyed sport activities.

Several types of interactions and events appeared to contribute to and maintain his behavior problems. These included task demands, adults failing to fulfill promises, delays in having requests fulfilled, and seeing peers engaged in sports that he could no longer do. A typical pattern was for Michael to make a request for an item or activity followed by his mother saying "no" or asking him to wait until another time or day. Michael would then escalate into behavior problems ranging from low (whine) to high (hit) intensity until his mother gave in to his demands. Peggy, through this form of coercive training by the child (Patterson, 1982), began to fulfill unreasonable demands at earlier stages in the escalating sequence of interactions. Another common pattern occurred when Michael refused to engage in tasks he didn't like, such as getting ready for bed. He would whine, scream, or hit a parent until the parent withdrew the task demand, delayed the non-preferred event (e.g. going to bed), or escalated into shouts, physical prompts, or corporal punishment.

Four hypotheses about the functions of Michael's behavior problems emerged from the assessment: (1) Michael whined, screamed, or hit to get attention or assistance; (2) Michael whined, screamed, aggressed, or engaged in destructive behavior to get an item or activity; (3)

Michael whined, screamed, aggressed, or destroyed to avoid a non-preferred task, activity, or person; and (4) Michael aggressed and destroyed to protest a loss of ability or opportunity.

These hypotheses served as the foundation for the design of a multicomponent positive behavioral support plan that addressed each purpose of Michael's problem behavior.

Family Ecology Assessment. Peggy was the primary participant in the interviews about the family's ecology, with Alan confirming information and describing his own experiences and perspective. Interviews about family characteristics and routines were completed across 4 meetings in the home. In the first 2 meetings, Peggy and Alan described their goals, strengths, resources and social supports, and stressors. During subsequent meetings, Michael's parents identified 4 family routines they wanted to improve, described the current structure of each routine, and generated a vision of what the routines would look like if they were successful.

The family assessment revealed that despite the presence of many stressors, the family had clear goals, possessed many strengths, and benefitted from several resources and social supports. For example, the family wanted Michael to learn to manage his own personal needs and free time, and to better tolerate errors, mistakes, and disappointments. His mother wanted other family members to share child care and household chores more equitably. The family had strong Christian values that encouraged family members to continue caring for each other despite the many difficulties they faced. On his own, Michael's father naturally used several effective strategies (e.g., telling Michael what to expect, offering calm reassurance) to help his son remain calm and cooperative. Informal resources used by the mother included help with child care and household chores from her husband and daughters. Effective formal resources included

Michael's teacher, who maintained excellent communication with Peggy. The family also received money from an insurance settlement that helped defray the costs that had been incurred since Michael's accident.

These positive characteristics provided a counterbalance to the stressors felt by family members: Michael's behavior problems, Peggy's exhaustion and frustration with the unequal distribution of child care tasks in the home, and Alan's sense of powerlessness in the family. Prior to the interview, Peggy and Alan thought their family had become totally dysfunctional; afterwards, they began to reframe their concept of their family as a healthy one struggling to overcome challenging yet definable obstacles.

During the discussion of family routines, Peggy and Alan decided to promote change in four routines that were not working well: (1) an early evening dinner routine in which family members sat together and ate in the dining room; (2) a homework routine in which Michael's parents helped him complete homework; (3) a middle evening leisure routine in which Michael attempted to entertain himself and interact with other family members; and (4) the bedtime routine in which Michael's parents helped Michael get ready for bed. Peggy first described each routine in terms of the elements of activity settings (e.g., goals, tasks, resources; O'Donnell & Tharp, 1990). Following her description, she then envisioned what each routine would look like if it were successful. During this exercise, the consultant encouraged Peggy to reconstruct the routine in her mind so that it was: (1) consistent with Michael's strengths and limitations, (2) congruent with family goals and values, and (3) sustainable over a long period of time. A description of the family's current and envisioned bedtime routine illustrates the process.

Peggy usually started the bedtime routine for Michael earlier than his two younger brothers (around 8:00 p.m.). Michael's bedroom was adjoined to his parent's bedroom and the living room where his younger brothers continued to watch T.V. or play together. The main resource to Peggy during the routine was Alan, who usually took over the routine when Michael began to "hassle" his mother. Meanwhile, her daughters were usually upstairs watching T.V. or in the dining room talking or snacking. They typically did not offer to help. The tasks in the routine were for Michael (with prompting from a parent) to go to his room, get his pajamas on, use the toilet if needed, brush his teeth and wash his face, and go to bed. Once in bed, Michael's father sometimes read him a story. Peggy's goals and values included: (1) Michael going to bed early; (2) the children going to bed clean, peaceful, and happy; and (3) Michael staying in his bedroom. Motives and feelings included Peggy worrying about how Michael would behave, wanting to get Michael "out of the way" so that she could get some rest, feelings of exhaustion, and resentment at the lack of help from other family members. Patterns of interaction during the routine were predominately negative: parent demands followed by child whining and aggression; and Peggy asking Alan for help after behavior problems escalated.

Having gained some insight into the family's current bedtime experience, the mother and consultant discussed what a successful routine would look like. Peggy envisioned a routine in which most elements were changed or expanded. Alan would help more proactively and more often. Her two daughters would help put the younger boys to bed. Goals would include a fair and predictable sharing of child care tasks, and Peggy having time after the routine to relax or talk with her daughters. Michael would complete routine tasks more independently and without

behavior problems. Positive patterns of interaction would include the family quieting down and cooperatively preparing for bed, and family members helping each other.

After a vision for each targeted routine was generated, the content and structure of each envisioned routine was discussed with other family members, and family members agreed to support efforts to achieve the vision. The consultant concluded the assessment by explaining how the information gained would drive the design of a behavioral support plan that would fit well with the family's lifestyle, and help them move toward their vision of family life.

#### Preliminary Plan Design

Based on assessment information the consultant (in continued dialogue with the family) designed a preliminary positive behavioral support plan and an implementation plan that described how interventions would be put into place. The consultant used the plan design guidelines described by Horner, et al. (1993) to select behavioral interventions, and used the guidelines described by Albin, et al. (in press) to ensure that interventions fit well with the characteristics and ecology of the family. Following is an abridged description of this process.

Positive Behavioral Support Plan Design. For each function of the child's behavior problems, ecological, antecedent, skill building, and consequent interventions were proposed that would make behavior problems irrelevant, ineffective, or inefficient for achieving their purposes. For example, Michael often engaged in behavior problems to obtain a preferred item or activity. Proposed interventions logically related to this hypothesis included: (1) making Michael's life more predictable by giving him information about when he can get preferred items and about when he can do preferred activities; (2) giving Michael a personal written schedule to use that

listed his responsibilities and rewards for completing them; (3) teaching Michael verbal negotiation skills including how to make reasonable requests, compromise, and accept limits; (4) using effective positive contingency contracts and praising attempts to use negotiation skills; (5) de-escalating behavior problems at an early stage (e.g., when he whined rather than when he aggressed); and (6) firmly telling him, after he aggresses, that he cannot get what he wants by using this behavior, and making sure that he does not get the desired item or activity for the rest of the day.

Goodness-of-fit was established by first ensuring that interventions advanced family goals, incorporated family knowledge and strengths, used resources available to the family, and appeared likely to diminish stressors. Peggy's goals included Michael becoming more independent during family routines, and herself getting more free time away from child care duties. To accommodate the child-centered goal, a personal schedule was proposed to help Michael self-manage his own bedtime routine. To accommodate the family-centered goal, the weekly use of skilled respite care was proposed so that Peggy could relax and pursue other interests on a regular basis.

Strengths of the family included the family's devotion to the Bible as a source of inspiration and wisdom, and the father's knowledge of several positive strategies for supporting Michael's participation in game activities, chores, and community outings. With the family's Christian values in mind, the consultant asked the family to identify quotes from the Bible that appeared consistent with the emerging support plan, and to use these quotes to fortify and inspire them in their effort to promote change. One quote Peggy found helpful was, "kind words are honey to



the soul and strength to the bones." When Peggy praised Michael's independent performance, she perceived her actions as not only technically correct but also inherently meaningful. The consultant also reflected on the father's use of effective precorrections during difficult tasks, and his use of calm reassurance, explanation, and redirection when Michael began to whine or grow agitated. These parenting skills became important features of teaching strategies and de-escalation procedures in the support plan.

Implementation Support Plan Design. Based on assessment information and discussions with Michael's parents and teacher, a preliminary implementation plan was designed that emphasized direct training support in the home, weekly phone consultation, family team meetings to discuss and role-play interventions and solve new problems, and continued counseling support. The family decided to first implement interventions in the bedtime routine, and then work on improving the leisure, homework, and dinner routines.

#### Team Meetings and Plan Finalization

Two team meetings were convened to review assessment information and finalize the preliminary positive behavioral support and implementation plans. The meetings were completed in 3½ hours. Meeting participants included Peggy and Alan, Michael's older sisters, his elementary school teacher, a middle school teacher who might assist with his transition to middle school, a TBI consultant to the family, and the family consultants. Michael did not attend the meeting because his family judged that his behavior would be disruptive and make meeting tasks difficult to complete.

The consultant summarized assessment and plan information on flip charts. Meeting participants first reviewed the functional assessment information and the hypotheses about behavior problems. After achieving a consensus on the reasons for Michael's behavior problems the team reviewed and discussed the interventions in the proposed behavior support plan and the support activities and roles described in the proposed implementation plan.

During the reviews and discussions the consultant answered team members' questions and concerns, encouraged suggestions for modifications, and acknowledged team members' contributions. Michael's parents and other team members agreed with the hypotheses about behavior problems and with most of the recommended interventions and support activities, and suggested some improvements. Michael's elementary school teacher also recommended that behavioral consultation meetings be held with middle school teachers and administrators before the start of the next school year to ensure a smooth transition. With team member recommendations incorporated, the plans were finalized. Soon after the meeting, the consultant wrote up the finalized plans and distributed them to team members. Summaries of the positive behavioral support plan and implementation plan are presented in Tables 1 and 2.

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Insert Tables 1 and 2 About Here  
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### Implementation Support

During implementation, the consultant helped the family put the plan into place. Over a period of 3 months, the consultant and the family first intervened in the bedroom routine, and

then initiated intervention in the leisure routine. Coaching in home routines and phone consultation typically occurred once per week. Coaching sessions lasted 1 to 1½ hours, while phone consultations lasted 15 to 30 minutes. Approximately once a month a team meeting was held with family members to discuss progress and role play interventions. Support activities used during implementation support are summarized below.

Embedding interventions in envisioned routines. The first task of implementation support was to identify relevant interventions from the support plan and effectively embed them in the first targeted routine -- going to bed. Toward this end, the consultant designed a brief, routine-specific plan that described interventions in terms of the content and structure of the bedtime routine. For example, one goal was for Michael to go to bed independently. Tasks included putting on his pajamas, completing hygiene tasks, and getting into bed. Behavioral interventions were embedded into the routine by teaching Michael to use a personalized self-management notebook that listed the tasks in the bedtime routine, and the reinforcers (e.g., bedtime story, dictate story for journal) available for going to bed cooperatively. The parents were also encouraged to praise Michael whenever he attempted to complete routine steps independently. To ensure that the routine included more frequent and predictable help from other family members, the family negotiated a weekly schedule of helpers and posted the schedule in the kitchen. To achieve the calmer atmosphere envisioned, Michael and his brothers began to go to bed at the same time (between 8:30 and 9:00 p.m.), and other family members agreed to keep activities in the living room quiet after 8:00 p.m.

Coaching. During the first few coaching sessions in the bedtime routine the consultant and family negotiated a style of coaching that was most comfortable to Michael and his parents. At the start of a session, the consultant asked Michael and his parents for their informed consent, and then met briefly with the parents to talk through the use of interventions. During the first few sessions, the consultant modeled the interventions with Michael while his parents observed. During subsequent sessions, the parents implemented interventions while the consultant observed or waited in another room until the routine was completed. After Michael went to bed, the consultant and parents briefly reviewed the session, emphasizing parent skillfulness and child progress.

Phone Consultation and Use of Implementation Checklist. During phone consultation, the consultant and the parents discussed progress in implementing interventions during the previous few days. An implementation checklist was used to structure the discussion. The checklist evaluated Michael's completion of routine steps, the parent's use of interventions, behavior problems, and the acceptability of the support effort (see Table 3). The parents described their successes, continued problems, and feelings or frustrations related to Michael and the support effort. The consultant commended the parents' achievements, helped solve new or recurring problems, and provided emotional support when a parent expressed grief over the child's accident, or frustration with recurring behaviors.

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Insert Table 3 About Here  
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Family Counseling. During natural opportunities that arose in coaching sessions, phone consultations, and family meetings, the consultants helped family members reframe their views of themselves, each other, and Michael. Peggy was encouraged to see herself as a person who proactively solved problems before they happened rather than worry about problems until they occurred. Through modeling and dialogue, the consultants helped family members see Alan as a competent leader in teaching Michael new ways to behave, rather than as a powerless father. Similarly, the family was encouraged to view Michael not as a damaged person but rather as a young boy striving to overcome obstacles to his development that frustrated and confused him.

Coordination of Lifestyle Goals and Transition to Middle School. Concurrent with direct and indirect support for family routines, the consultants and the family collaborated to implement lifestyle interventions such as increasing Michael's friendships and getting skilled respite care into the home on a regular basis. The consultants, for example, collaborated with Peggy to enroll Michael in a summer church camp for non-disabled children, and provided consultation support to the camp counselors. Michael also became a participant in a project whose goal was to help children with TBI develop friendships. During implementation support the consultant facilitated meetings between Peggy and the director of a respite care program, and participated in discussions about the development of skilled respite care for Michael.

At the start of the new school year, the consultants met with school personnel at the middle school, discussed the family's progress, gave the receiving teacher a copy of the behavioral support plan, and discussed interventions that would be relevant to the school setting. In all conversations with school personnel the consultants emphasized the parents' expertise in

supporting Michael, and encouraged administrators and teachers to view Michael's family as a valuable resource to the school, and as able collaborators in the coordination of support between the home and school.

#### Termination of Implementation Support and Follow-up

Following 7 weeks of implementation support in the bedtime routine (involving  $\approx$  17 hrs of direct and indirect support), and 5 weeks of implementation support for the leisure routine (involving  $\approx$  12 hrs of primarily indirect support), the family chose to terminate their participation in implementation activities, except for continued phone consultation on an as-needed basis. Their reasons for terminating most implementation support included improvements in Michael's behavior across all routines, family confidence that they could continue supporting Michael without intensive, direct intervention in the home, and Peggy starting a new job and wanting to simplify her life. The consultants supported the family's decision to terminate implementation support, contacted the family by telephone approximately once a month to assess the maintenance of behavioral improvement in Michael, and completed follow-up measures 2, 3, and 5 months after implementation support ended.

#### Evaluation Methods

Four methods of evaluation were used: (1) A single-case research design summarized direct observations of behavior problems in four family routines; (2) implementation checklists assessed parent fidelity in use of interventions; (3) a social validity measure evaluated the acceptability of plan goals, procedures, and outcomes; and (4) qualitative interviews provided an

interpretation of the family's subjective experience of the support effort. Evaluation methods are summarized below.

Single-case Research Design. A single baseline, time series research design (Barlow & Hersen, 1984) was employed to assess the correlation between implementation of the behavior support plan, and improvement in child behavior in the dinner, homework, leisure, and bedtime routines. The quasi-experimental design had three phases; baseline, intervention, and follow-up. Direct observation of child behavior across the 4 routines was completed by trained observers during each observation session. Three behaviors were operationally defined: (1) aggression, including hitting, kicking, and biting; (2) destructive behaviors including throwing objects, knocking objects off tables or counters, and breaking objects; and (3) screaming, involving high intensity shrieking or shouting. An interval recording method of observation was used, and observations in each routine lasted for 15 minutes. During an observation session, the observer used a clipboard with an earphone attached that emitted a beep every 30 seconds. Following each interval, the observer recorded whether or not behavior problems occurred during the interval.

Observers participated in 10 hours of training including discussion of definitions and procedures, and pilot observations in targeted routines until interobserver agreement scores of 85% or better were achieved. Interobserver agreement was measured in 6 of the 17 (35%) observation sessions, and agreement measures were distributed across the 3 phases of the study. Average interobserver agreement for behavior problems was 88% (range, 79%-99%).



Implementation Fidelity. During phone consultations about intervention in the bedtime routine, the consultant used an implementation checklist to guide an interview with Michael's parents about use of interventions. The family evaluated fidelity using a 5-point Likert scale (1 = not able to use, 5 = used very well). Michael's parents completed this interview on four occasions.

Social Validity. The social validity of the support effort was evaluated during intervention in the bedtime routine and after follow-up measurement. During the parents self-evaluation of the bedtime routine, they also rated statements about the acceptability of the routine (e g., family members helped, all children went to bed happy) using a 5-point Likert scale (see Table 3). Two months after the last follow-up observation, Michael's mother evaluated the social validity of the overall support effort using a 10 item questionnaire with a 6-point Likert scale (1 = disagree, 6 = agree). The items addressed issues related to the acceptability of support plans goals, procedures, and outcomes.

Qualitative Interviews. Once during implementation support and once again during follow-up, Michael's parents were interviewed about their perceptions of the support effort. The consultant asked 3 open-ended questions: (1) How has Michael's behavior and lifestyle improved since the support effort began, if at all; (2) how has the family's lifestyle improved since the support effort began, if at all; and (3) what problems continue to occur? The first interview was for 45 min, and the second interview lasted 1 hour. The interviews were tape recorded and transcribed. These data then were analyzed for descriptive themes using qualitative

methods of analysis (Gilgun, Daly, & Handel, 1992). Themes that emerged from the data were summarized into a brief interpretation of the family's experience.

### Results

Behavior Problems. Data collected across the four routines were combined into a composite percentage of intervals of behavior problems. The composite percentage of intervals with behavior problems across the 4 family routines is presented in Figure 1. Overall, the data indicate significant improvement in the level, trend, and stability of behavior problems across the 4 targeted routines after the positive behavioral support plan was implemented in the bedtime routine, and subsequently (albeit briefly) in the leisure routine. Baseline data show high variability, an increasing trend (split middle method of trend analysis [Tawney & Gast, 1984]), and an average percentage of 10.6 of total intervals evidencing behavior problems. During implementation support, behavior problems fell to a stable average of 1.5% of total intervals observed, and evidenced further improvement (0.5%) 2 and 3 months after implementation support was concluded. Because the data represent a composite percentage across 4 routines, an interpretation of behavior change in any one routine cannot be made. Also, because of limitations inherent in the research design, these changes suggest only a correlation between implementation of the positive behavioral support plan and improvements in child behavior across the 4 routines. A casual relationship cannot be inferred.

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Insert Figure 1 about here  
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Implementation Fidelity. Across 4 ratings (1 = unable to do; 5 = did very well) during implementation support in the bedtime routine, the parents evaluated themselves as increasingly able to implement interventions. During the first self-evaluation the average rating was 3.3, but improved to 4.2 by the last evaluation. These data suggest that the parents perceived themselves as becoming more capable of using interventions effectively in the bedtime routine.

Social Validity. Across 4 ratings (1 = disagree; 5 = agree) of the bedtime routine, Michael's parents indicated that: (1) the routine was not so stressful (2.6); (2) interventions were not difficult to implement (1.5); (3) children went to bed fairly happy (3.8); and (4) they had time to relax (4.2). The parent's evaluation of the comprehensive support effort is presented in Tables 4 and 5. These data suggest that, overall, the family was very satisfied with support goals, interventions, and outcomes.

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Insert Tables 4 and 5 here  
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The Parents' Experience: "He Fits into the Family Better." The qualitative findings served to confirm and further illuminate improvements in Michael's behavior, parent use of behavioral interventions, and overall improvements in the family's lifestyle. The findings also revealed areas where little progress was made and where family problems remained.

Michael's parents consistently reported that Michael was calmer, more cooperative, and more independent in many areas of his life than he had been before the support effort. His parents experienced him as less "whiny" and less apt to escalate into aggressive behaviors. They

estimated that major behavioral incidents had decreased from about once a week to once or twice a month, and that behaviors during an incident were less intense.

Michael's parents partly attributed his gains in independence to changes they had made in themselves. They saw themselves as more patient with him, not expecting him to complete tasks as quickly as he did before the accident. They also noted that they were giving Michael more opportunities to do things for himself. For Michael's part, they perceived a renewed willingness and ability to do things independently. Peggy explained what she meant by independence:

It means he doesn't need our help as much. He's able to know what he has to do and do it while I can help other members of the family. It means he can take care of himself as far as getting dressed. He's not as demanding or whiny. I don't have to drive him to do things like .. get ready for bed. He's just more confident about the fact that he can do things and that he's part of the family.

His parents also experienced Michael as more willing and able to negotiate wants and to accept compromises or limits. He was viewed as listening more, reasoning better, and trying to understand why he wasn't allowed to do certain things.

Both parents reported that Michael was doing well in middle school, liked his middle school teacher, and had begun to make friends at school. They viewed his teacher as very dedicated and skilled. Although Michael was perceived as having friends at school, his parents reported that he still did not have "after school" friends. A remaining source of frustration and anger for Michael was seeing his younger brother having friends over or leaving the house to visit friends.

Michael's parents viewed themselves as much more effective at parenting Michael. They found themselves using praise, positive contingencies, and precorrections to build cooperation and independence. Peggy described how she often praised him for doing things independently

around the house: "I'll say, 'it really helps me when you have the table all set -- all I have to do is get the milk'." His parents also said they were better at de-escalating problems by remaining calm themselves, by not worrying so much about Michael "losing it," and by providing information, reassurance, or redirection before he escalated. Finally, his parents observed that they had become consistent about not giving into Michael when he tried to use behavior problems to enforce his will.

Alan and Peggy described a few improvements in the quality of the family's life together since the start of the support effort. They believed that their relationship had improved, and that they were more supportive of each other. Peggy said she was able to get more rest because Michael's behavior was more predictable, and he was more able to manage his free time. Alan said he was able to take Michael on outings with the other boys successfully because he always told Michael what to expect, and made sure he rewarded the boys for cooperating together. Unsolved problems in the family included Michael's relationship with his 8 year old brother, which remained competitive and contentious, and the continued isolation of the two older daughters from Michael and the rest of the family.

### Conclusion

This chapter describes a comprehensive approach to intervention with families of children with TBI and behavior problems that combines current best practice in positive behavioral support, family support, and behavioral parent training. Implementation of the approach was associated with clinically significant improvements in child behavior that maintained during follow-up measures three and four months post intervention.

Four contributions of the family support approach to the TBI rehabilitation field bear emphasis. First, the approach synthesizes a behavior analytic understanding of child behavior problems with an ethnographic view of family ecology and culture. This synthesis contributes to the design of multicomponent positive behavior support plans that are both effective and contextually appropriate for children with TBI and their families.

Second, functional assessment with children experiencing TBI, while acknowledging the influence of trauma on the development of behavior problems, suggests that additional factors influence the development and maintenance of problem behaviors (O'Neill et al., 1990; Wacker et al., in press). These factors include the child's skill deficits, changes in parent-child interaction patterns such that behavior problems are inadvertently strengthened, and decreases in the child's quality of life. The benefit of this expanded view of factors related to problem behaviors is that each skill deficit, detrimental social interaction pattern, or lifestyle loss can be linked to an intervention that may reduce problem behaviors and rebuild adaptive behavior. Families of children with TBI can take heart in a functional perspective on problem behaviors (Carr, Robinson, & Wray Palumbo, 1990). Through this perspective parents may see that (1) their child's behavior problems often serve a clear purpose (i.e., escape demand, get help), (2) problem behaviors are typically triggered by observable events in the environment, and (3) the trauma to the child need not be a solid barrier to behavioral rehabilitation. Empowered by this perspective, families can collaborate with interventionists to design acceptable and effective interventions that address each purpose of the child's problem behaviors.

Third, the collaborative approach to assessment of family ecology naturally encourages professionals to listen to families because this is the only efficient way to gain an in-depth understanding of family characteristics (e.g., goals, strengths, stressors) and family routines (Gallimore, Weisner et al., 1993; Summers et al., 1989). Thus the assessment process inherently honors the family. Several benefits accrue from an assessment approach that may be experienced by families as empowering (Turnbull & Turnbull, 1991c). The development of a therapeutic alliance may be facilitated. A dialogue about family strengths may rekindle the family's sense of hope and self-confidence. An understanding of family routines may lay the groundwork for the design of behavioral interventions that are specially tailored to fit well with the features of the routines.

A final contribution is viewing the family routine as the unit of analysis and intervention (O'Donnell & Tharp, 1990). Because family routines include many of the relevant features of the child's problem behaviors and the family's ecology, intervening within a routine can be a highly efficient and effective means for promoting initial change that the family can see, understand, and attribute to their own effort. For example, when Michael's family successfully intervened in the bedtime routine, they not only improved their son's problem behaviors and their parenting practices; they also improved several other relevant features of family ecology (e.g., equity between mother and father, mother's need for free time, Michael's status vis a vis younger brothers). Equally importantly, the focus and continuity that intervention in one routine provided, allowed Michael's parents to recognize their new found ability to transform a failed routine into a successful one.



Research design and outcome limitations suggest the need for caution when interpreting results. The case study design does not permit certainty about attributing behavioral improvement to the support process. Other factors occurring at the same time as the intervention may also account for improvements in Michael's behavior. Also, although 3 and 4 month follow-up data are encouraging, these data are not sufficient to comment on the long term durability of the support effort. A technology of positive behavioral support and the design of contextually appropriate support plans should promote meaningful change that endures for many years.

A related caution is that the positive behavior support approach did not "cure" Michael of problem behaviors. His continued success at home will depend on the extent to which family members continue to support him effectively. Because threats to maintenance are numerous in family settings (e.g., fatigue, illness, marital distress; Griest & Forehand, 1982) interventionists will do well to consider ways to support the long term maintenance of positive outcomes. One approach that may have promise is to build periodic follow-up support into a long-term model of support to families (e.g., once every 6 months for 3-5 years).

Future research should replicate the support approach with other families of children with TBI to better demonstrate the efficacy of the approach, and to demonstrate its utility across a diversity of families. Such research should include long-term follow-up measures to better evaluate the durability of multicomponent interventions.

In conclusion, the results, although requiring some caution in their interpretation, nevertheless suggest the promise of the comprehensive family support approach for ameliorating behavior problems in children with TBI, for helping families reintegrate their child with TBI into

valued family routines, and for rebuilding the stability and cohesion that typically characterizes families before the trauma to the child and family.

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Table 1

Multicomponent Positive Behavioral Support Plan

Family-Centered Interventions

1. Plan for skilled respite care at least once a week.
2. Share child care and housecleaning tasks fairly and predictably so that each family member can rest.

Child-Centered Interventions

Lifestyle/Ecological

1. Help Michael feel important (e.g., offer choices and honor reasonable preferences; patiently listen to him; let him do things on his own without unwanted assistance)
2. Support Michael in the development of friendships with non-disabled peers.
3. During major transitions (e.g., back to school after a holiday) increase choice and reinforcement.

Antecedent/Proactive

1. Have Michael use a self-management schedule that reminds him of tasks, social rules, and available reinforcers during routines at home and during classes at school.
2. Provide precorrections before he makes social errors or acts impulsively in the community
3. Support Michael when he does homework by helping him in a quiet room, by interspersing easy/fun tasks with new/difficult tasks, and by using humor to keep the atmosphere lighthearted.

Teaching New Behaviors/Skills

1. Teach Michael to self-manage his schedule of tasks and activities.
2. Teach Michael to negotiate choices and accept compromises and limits.
3. Teach Michael to control his anger by teaching him to say "No big deal" when he makes a mistake, to do deep breathing if he feels upset, and to find an adult to talk to about the problem.

Positive Reinforcement

1. Praise Michael often for trying, independence, and showing self-restraint
2. Use effective positive contingency contracts, and follow through consistently.

De-escalation Strategies.

1. Before Michael escalates: (a) assess the reason for his agitation and use a support strategy that matches the reason; (b) remind him to use his skills instead of his behaviors; (c) prompt or model the use of the appropriate skills; (d) praise remaining calm and trying to use skills; (d) redirect him back to task or activity; and (e) praise re-initiating task or activity.

Negative Consequences.

1. If Michael escalates to get an item or activity: (a) calmly but firmly say, "No"; (b) redirect him to a dissimilar task or activity; (c) remain calm, firm, but sympathetic; and (d) do not negotiate.

2. If Michael escalates to get attention: (a) Calmly but firmly say, "No."; (b) walk away for one to two minutes; (c) return and remind him of rule; (d) tell him when you can give him attention; and (e) redirect him to an activity he can do independently.

Table 2

Implementation Plan

Support Activities (5 month timeline)

1. Written positive behavioral support plan
2. Routine specific plan with implementation checklist
3. Coaching in targeted routines, one at a time (1x/week)
4. Phone consultation (1x/week)
5. Family team meeting to discuss and role play interventions (1x/4-6 wks)
6. Counseling support
7. Friendship development support
8. Transition support to middle school

Roles and Responsibilities

1. Parents: Primary implementors of interventions.
2. Daughters: Informed participants; secondary implementors.
3. Behavior consultant: Primary implementation support person; respite care support and development; support for transition to middle school.
4. Family counselor: Supervisor of clinical support effort; support for lifestyle changes; counseling support.
5. School teachers: Support for transition to middle school; implementation and adaptation of interventions in the school.
6. TBI consultant: Life-planning support; long term social support.



Table 3

Implementation Checklist for Bedtime Routine

<u>Six Steps to a Harmonious Bedtime Routine</u>	Unable to do this	Did this very well
1. Reviewed schedule and rules with Michael.	1 2 3 4 5	
2. Offered choice of reward for independence and cooperation.	1 2 3 4 5	
3. Only provided help if needed.	1 2 3 4 5	
4. Praised independence and following social rules.	1 2 3 4 5	
5. If Michael calmly went to bed, I fulfilled the deal.	1 2 3 4 5	NA
6. If Michael hit, kicked or threw things, I did not fulfill the deal.	1 2 3 4 5	NA
<u>How Michael did during routine</u>	Much help	By self
1. Completed the routine with little.	1 2 3 4 5	
2. Calmly said goodnight and prepared to sleep.	1 2 3 4 5	
3. Whined/screamed (# of times).	0 1 2-5 6-10 10 or more	
4. Hit, kicked, threw something (# of times).	0 1 2-5 6-10 10 or more	
<u>How I feel about the bedtime routine</u>	Disagree	Agree
1. The routine was stressful.	1 2 3 4 5	
2. The steps to success were difficult to implement.	1 2 3 4 5	
3. All children went to bed happy.	1 2 3 4 5	
4. I got some relaxation time.	1 2 3 4 5	

Table 4

Social Validity Evaluation: Ratings (1 = Disagree; 6 = Agree)

1.	Goals were appropriate	6
2.	Goals were consistent with my family's values	6
3.	Interventions were difficult to carry out	3
4.	Interventions were effective in improving child's behavior	6
5.	Outcomes were beneficial to my child	6
6.	Outcomes were beneficial to my family as a whole	4
7.	The plan caused unanticipated problems in my family.	1
8.	Training activities were well organized and helpful	6
9.	The consultants showed respect for our values	6
10.	Overall, the support effort strengthened my family	6

Table 5

Social Validity Evaluation: Parent Comments

1. We have been successfully taught how to look for and recognize the signs of potential problems that could escalate into inappropriate behavior in our child and how to redirect him in a more positive manner.
2. We are sometimes lulled into forgetting the strategies because Michael behaves so well for longer periods of time and when he or we have a bad day, it takes some quick thinking and attitude adjustments on both parts.
3. Michael is much more cooperative, independent, calm, and pleasant to have around.
4. Living with the pressures and demands of a head injured child along with 4 other siblings will always be stressful but this support has been essential in helping us as parents cope and alleviate a major part of that stress.

Figure Captions

Figure 1. Percentage of intervals with behavior problems during 4 home routines: Dinner, homework, leisure, and going to bed.

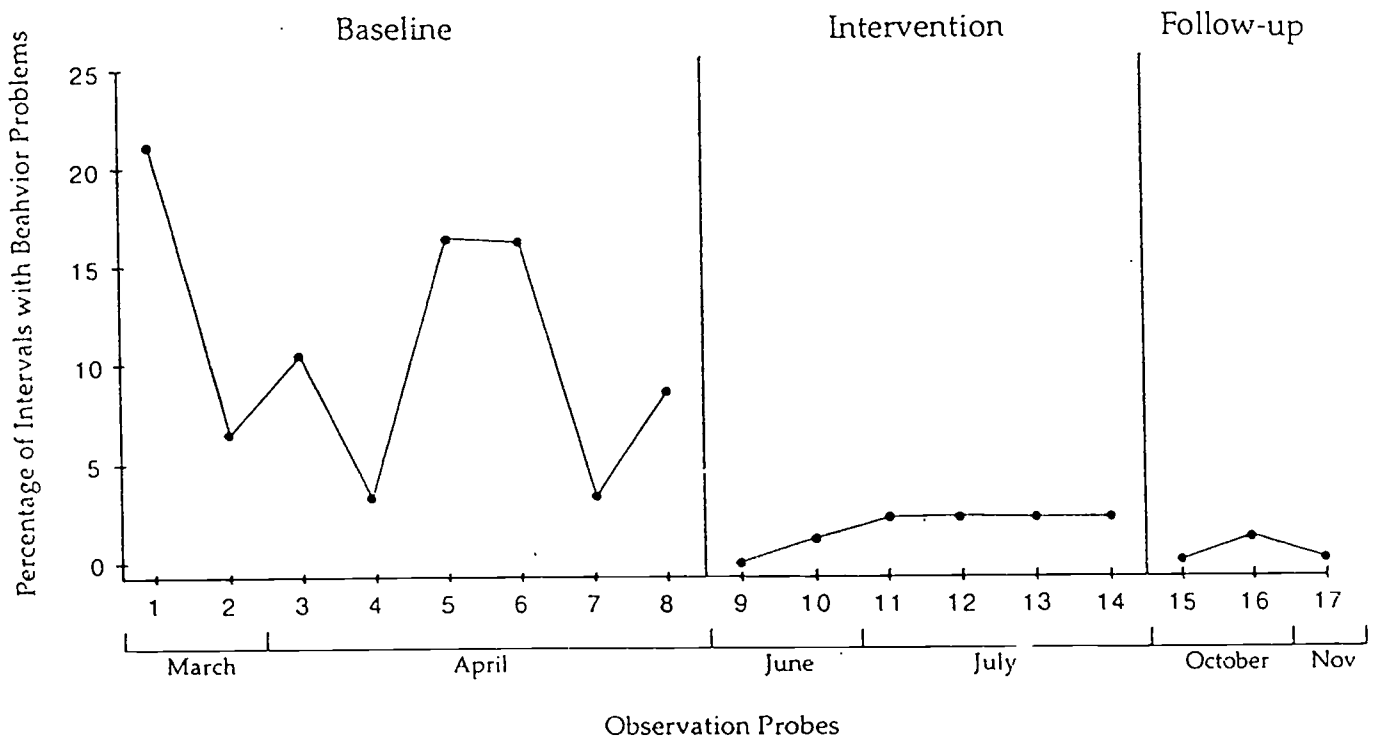


Figure 1. Percentage of intervals with behavior problems during four home routines; dinner, homework, leisure, and going to bed.

**Helping Parents Negotiate the School System**

Helping Parents Negotiate the School System

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## Helping Parents Negotiate the School System

Once a child returns to school following a brain injury, the educational system becomes the primary service provider for that child (Savage & Wolcott, 1994; Ylvisaker, Hartwick, & Stevens, 1991). Because most children and adolescents make excellent physical recoveries after brain injuries, it has been assumed that their return to school would be relatively smooth (Lehr, 1990), and that their educational needs could be addressed by existing regular and special education practices. It is only recently that medical and school personnel have realized that many students experience a range of unique challenges when they return to school.

An increasing number of articles in the past several years have been devoted to effective educational programming for students with ABI. Authors have offered detailed guidelines in the following areas: evaluation (Begali, 1994; Savage & Carter 91), placement (Cooley & Singer, 1991; Savage & Carter, 1991); transition from hospital to school (Savage & Carter 91; Lehr, 90; Savage, 91; Ylvisaker, Hartwick, & Stevens, 1991); modifying educational environments (Blosser & DePompei, 1994; Cohen, Joyce, Rhoades, & Welks, 85; Cohen, 91) specific instructional and behavioral strategies (Blosser & DePompei, 1994; Cohen, 1991; Glang, Singer, Cooley, & Tish, 1992; Deaton, 1994; Light, Neumann, Lewis, Morecki-Oberg, Asarnow, & Satz, 1987; Savage & Wolcott, 1988) and transition to post-high school education and employment (Nordlund, 1994, Condeluci, 1994).

The success of the school experience for most children may depend not only on the strategies employed in the school setting, but on the advocacy skills of their parents. Parents who are knowledgeable about the kinds of services and approaches that can help their child, and who effectively advocate for them will be more satisfied with their child's educational program (see Lash, this volume). As one mother said:

I don't know if my son's school ever had students with traumatic brain injury..Because I was an educator, because I am an advocate for my child, I think I forced them to look at the issue. But, most people wouldn't go through what we went through...We became the clanging bell...the parents that they could never please.

The purpose of this chapter is to present an analysis of current educational services for students with TBI from the eyes of those who have most at stake in the success of these services: children, parents and educators. This chapter will present results from several pilot surveys that asked parents and educators to identify the strengths and weaknesses of current educational services for students. Information gathered from qualitative interviews and participant observation will expand on the survey results. Guidelines for addressing some of the key challenges identified and helping parents effectively negotiate the school system to achieve successful school experiences for their children will be offered.

### The Challenge of ABI: Child, Parent, and Educator Perspectives

Developing an effective educational program for a student with ABI presents a challenge for everyone involved. At the center of the challenge is the child or adolescent, who returns to school as a different person, with changes in nearly every aspect of his or her life. Each child or adolescent experiences differing cognitive, behavioral, physical, and emotional alterations as a result of brain injury; the effects of these changes will produce life-long changes in the child's self-concept. For example, one adolescent talks about how the effects of his injury affected his career plans:

I've always known I was going to go to college. I didn't know what I was going to do....After my head injury, a lot of my problem solving and cognitive (abilities)....for English and spelling..and that basic core curriculum--that was a lot harder for me, so I didn't enjoy it anymore. So that kind of eliminated that area of career choice....but one thing that wasn't really hampered was creative ability. .... That's what I was left with, so I kept working with it and now I love it, so....that's why I'm planning on going into it.

Almost all children and adolescents will also notice dramatic shifts in their social support network (see Singer & Nixon, this volume; Thomsen, 1974; Willer, Allen, Durnan & Ferry, 1990). As one adolescent reports:

It's like my life had changed after my head injury...it was real hard to deal with people that were used to me being a different way than I was. And, there were things that they expected that I couldn't do...I wasn't in a

wheelchair...and I didn't have scars on my head...(so) they couldn't see that I had some real disabilities.

Social isolation can become more extreme over time, as students with TBI miss out on opportunities to learn age-appropriate social skills and therefore engage in social behaviors that their peers find bizarre or offensive. The following description from a series of participant observations illustrates this problem.

*At age 13, six years after his head injury, Mike became interested in girls. At first his interest was manifested by staring intently at certain girls in classrooms and between classes, Later, observing the behavior of his peers, Mike started making sexually suggestive comments as girls walked by. However, unlike his peers comments, Mike's comments were audible to the girls. Mike also repeatedly sent friends to tell a girl that he wanted to go out with her, much to the girl's embarrassment. In one class he continually whispered to the girl sitting in front of him, "Let's do it!. Want to do it with me? When can we do it?" The girl found his remarks threatening and offensive and complained in tears to the teacher about Mike's behavior.*

Not only are children coping with the many changes resulting from injury, but this process of improvement following brain injury is superimposed on the overall process of child development (see Lehr, this volume). The dual-pronged nature of the rehabilitation process can be particularly problematic for adolescents. The cognitive, behavioral, and social challenges they face are exacerbated by the increased demands of secondary settings (Ewing-Cobbs, Fletcher, & Levin, 1985; Rosen & Gerring, 1986). Students must operate in larger schools with more complex scheduling and more difficult logistical demands. There are also more peers to interact with, at a time when all students face the dramatic developmental changes and insecurities of adolescence. Most importantly, students with TBI are expected to function more independently in these new and complex environments. As students transition to middle and high school settings, not only must they manage the complicated details of this demanding environment, they must also demonstrate that they are developing skills necessary for adulthood: learning to solve problems on their own, and to

handle the frustrations of this difficult time with decreasing assistance from adults.

Educator's perspective. For the educator, the student with ABI presents a complex constellation of needs. Most educators have not received training in acquired brain injury (Savage, 1985) and feel unprepared to meet these students' needs (Cooley & Glang, 1994; Savage & Carter, 1991). Moreover, the heterogeneity of the TBI population makes these students particularly challenging for general educators; no one approach, strategy, or curriculum is appropriate for all students in this group (Cooley & Singer, 1991). Reflecting on her year-long experiences with a particularly challenging student one teacher said:

He's the only identified child with TBI we had...and we didn't know what to do with him.

Lack of awareness of the range of effects of TBI and how these might be manifested in student behavior also contributes to educators' difficulty in meeting student needs. A teacher who struggled with the severe behavior problems of one of her students reported:

I called his mother recently. As it turns out, he had a severe head injury five years ago and maybe that has something to do with it, I don't know. His mother explained that these episodes are usually set off by stress and a warning sign that he's going to have a tantrum is that he gets a severe headache. Well, I never put any stress on him. I have the same expectations for him that I have for all my other students. Besides, once he said he had a headache, but when I sent him to the nurse, boom, within two minutes he was playing with another boy that was down there. I'm not buying the head injury aspect, I think he's just trying to get out of doing his work.

Parents' response. Parents encounter an on-going source of stress when their child returns to school. In addition to the financial and emotional burdens involved with coping with ABI, parents now face the added stress of working with school professionals (who may or may not be knowledgeable about brain injury) to access needed educational services for their child. Because prior to the

injury most children with ABI progressed normally through school, parents may be unfamiliar with their rights under the Individuals with Disabilities Education Act of 1990 (PL 101-476) , and many find the system unwieldy. In addition, parents may find that schools can provide a much lower level of services than was provided in the rehabilitation setting, particularly in the areas of physical, occupational, and speech therapies (Lash & Scarpino, 1993). As a result, parents may make what appear to be unrealistic demands for services, which can cause a defensive response by school personnel, and sets an adversarial tone for parent-professional interactions.

Unfortunately, parents are forced to become an advocate for their child at a point when parents are overloaded and ill-prepared to become involved in such a complicated process (Savage & Carter, 1991). As one parent reports, her first encounters with the educational system came at a very stressful time:

....all of our efforts had been in trying to keep the rest of the family healthy, trying to keep our marriage alive....

Another parent began her role as advocate following a car accident in which her husband was killed, both of her children sustained head injuries, and she herself was injured.

The stresses parents must cope with do not diminish once the child or adolescent has successfully transitioned to school. At the beginning of each new school year (and in many cases, the beginning of each new school term), the child and parents must learn how to negotiate a new schedule, become familiar with new teachers' classroom systems, and learn to work collaboratively with a new group of professionals. In reality, then, the transition to school really does not fully end until the child has left the public school system.

Parents who are strong advocates for particular services for their children are sometimes labeled by school personnel as being "in denial" about the severity of their students' cognitive disabilities or inappropriate behaviors. When asked how she handled such negative perceptions, one mother, who had adopted 10 children with head injuries said:

I begin every meeting with a new school representative by saying, 'Everything you've heard about me is true: I'm in denial, I'm a crazy lady, I'm unrealistic. Now, let's get down to business.'

Another mother who felt responsible for the accident that caused her daughter's head injury in infancy said:

I finally sat all the school people down and said, 'Look, I'm motivated by guilt, and you should know that because of that, I'm not going to stop hounding you until give my daughter the services she needs.'

### Pilot Surveys

A range of problems with the way schools serve students with ABI have been identified in the literature (e.g., Cooley & Singer, 1991). In an attempt to ascertain parent and teacher perspectives of current educational services, two pilot surveys and a series of focus groups and qualitative interviews were conducted.

Parent survey. In the fall of 1993, 31 parents throughout the northwest completed a questionnaire about their child's educational experiences. All but 2 of the parents had a child who had survived a traumatic brain injury more than 2 years prior to completing the survey (the children of the remaining 2 parents were more recently injured). The children ranged in age from 5 - 21. Six of the children were currently served in inclusive settings with non-handicapped peers; 15 were placed in self contained or pull-out programs; and the remaining students were no longer attending public school.

All of the parents felt that brain injury had significantly impacted their child's educational experiences. The parents identified problems with organization and planning, memory, behavior, and social isolation as barriers to successful experiences.

Most of the parents were dissatisfied with how well the school addressed their child's educational needs. Table 1 shows how parents rated the schools attended by their children in six domains. The only domain where parents felt schools were doing a satisfactory job was in making the school physically accessible; in all 5 of the other domains, parents rated schools as doing a less than satisfactory to poor job.



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Table 1 Parent's rating of school's performance in 6 educational domains (N = 26)

---

1		5
School does a poor job		School does a great job
	<u>Mean rating</u>	<u>SD</u>
Making the school physically accessible	4.15	.89
Training teachers to understand TBI	1.89	1.14
Dealing with social and behavioral problems	2.16	1.27
Dealing with memory and learning problems	2.4	1.2
Helping child/adolescent become independent	2.8	1.2
Communicating with family about coping with TBI	1.92	1.14

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The respondents identified 2 key reasons for the school's unsatisfactory performance--limited staff knowledge of TBI and its related effects (46%), and limited resources (24%). When asked what they might recommend to their child's school to improve services for students with TBI, 15 of the parents recommended more training for teachers and related service staff serving students with TBI. A number of the parents suggested that schools improve communication with parents. Parents commented that schools would be more



successful in designing educational programs if they worked more closely with parents. For example, one parent wrote:

(Schools should) communicate more with the child's parents, and consider the parents to be the child's key link between the child's educational experience. (They should) listen to parents, they do know their child.

To further explore parent perspectives, a focus group was conducted with a sample of parents who had responded to the survey. In the focus group, parents consistently reported feeling frustrated with their children's school experiences. This occurred in spite of the fact their children were quite diverse, representing a variety of ages, etiologies, levels of functioning and time post injury. As described by the parents, the obstacles to successful school experiences could be classified into four categories: 1) educational barriers produced by the child's memory/organizational impairments, 2) problems due to students' poor social integration, 3) difficulties produced by teachers' misperceptions about brain injury, and 4) frustrations related to schools' inability to adjust their regimen to the needs of the student.

Several parents made comments about a particular teacher or administrator who demonstrated a caring attitude; however, there were virtually no descriptions of positive actions taken by a school or classroom teacher that resulted in more effective educational experiences. The parents themselves had generated and shared with teachers many helpful strategies, but for the most part, these were not implemented in the school settings. For example, one parent described the importance of her son taking a short break when he felt overwhelmed by too much information. This strategy had been quite effective during her son's therapy sessions in the medical setting. When this idea was posed to her son's teacher, it was rejected as the teacher felt it might set an undesirable precedent for other students. Other representative comments from parents include:

His teachers tended to only focus on the fact he had previous behavior problems and didn't recognize the contribution of the head injury

Every day is different for my child depending upon his fatigue, stress, etc.--when he performs differently in different classes they think he isn't trying

The principal said the regular teachers in the 6th grade did not want to do the extra stuff for my son so that we should wait till the 7th grade when there were some teachers who were more supportive of handicapped kids

Educator surveys. The results from the parent survey are consistent with earlier reports that educators are not knowledgeable about TBI and do not feel prepared to manage the range of problems experienced by these students (Cooley & Glang, 1994). In a state-wide survey of 183 educators designed to ascertain educators' knowledge about and perceptions of students with TBI, respondents scored moderately low on a measure of knowledge (mean score was 71%). When these same educators were asked to rate how prepared they felt to meet the needs of students with TBI (on a scale of 1 - 5, 1 = not at all prepared, 5 = very prepared) the average rating was between 2.9 - 3.3, or only "somewhat prepared." Ratings were consistent across behavioral, academic, social, and cognitive domains. As a group, regular educators consistently rated themselves as feeling less competent than did special educators and other consulting and administrative professionals. An interesting finding showed that for this group of educators, knowledge and perceived competence were negatively correlated: those professionals who scored highest on the knowledge quiz reported feeling the least competent.

A second educator survey was conducted in the spring of 1993 in conjunction with a regional workshop on TBI. Thirty-four educators who had experience working with students with TBI completed a questionnaire about their perceptions of the challenges of serving this population. Like the parents surveyed, these educators listed many of the same cognitive deficits identified in the literature as obstacles to success in school for children with TBI. On a scale of 1 - 5 (1 = not descriptive, 5 = very descriptive), respondents rated problems with memory (4.0), attention (4.0), generalization (3.87), problem-solving (3.82), and learning rate (3.76) as being barriers to successful school experiences.

Educators' lack of awareness of the effects of ABI can interfere with effective delivery of services for students (Rosen & Gerring, 1986; Todis & Glang, 1994).

Field notes from classroom observations of one middle school student provide an example:

*Mike is fully integrated into mainstream classes, receiving support from special education staff. A recent assignment for English, creating a brochure "All About Me," was one that the special education teacher felt was "perfect for Mike," given his artistic ability. He had ample time to work on the brochure in class over a two-week period, and special education assistants and teachers checked with him daily, asking how his project was coming. They were stunned when the day before the project was due, Mike asked one of them, "What are we supposed to do on this project thing?" The special education teacher expressed her dismay: I had been told that students with head injuries sometimes have trouble with 'initiation,' but I guess I didn't understand that meant that he literally would not be able to get going on this without very direct support. Also, when we check in with him, I guess we have to do a lot more than ask, 'How's it going, Mike?' Because he always says 'Fine,' and maybe he really thinks everything is fine. But we need to actually see his work, see what he's done.*

A mother of a fourth grade girl told of how she had asked her child's teacher why she was still adding only single digit figures at school, when at home she had demonstrated more advanced math skills using the computer. The teacher explained that the hospital representative who had conducted a one-hour inservice injury for the staff to ease the girl's transition from hospital to school had told the teacher that it was important for Jane to experience success in her schoolwork. The teacher had interpreted this to mean that Jane should be given only tasks that she already knew how to do. As a result, Jane had received no new instruction in the two years since her return to school.

Results from surveys, focus groups, and qualitative observations suggest that neither educators nor parents are satisfied with the ways students with ABI are served in schools today. Efforts to improve services must include changes on the parts of both educators and parents.

#### Improving Educational Services: What Educators and Parents Can Do

Few educators have an understanding of the complex and unique issues faced by the growing population of students with ABI (Blosser & DePompei, 1991; Lash

& Scarpino, 1993; Ylvisaker et al., 1991). Acquired brain injury is an under-addressed topic in university teacher training programs; only 8% of graduate programs in Special Education provide training in TBI (Savage, 1985). Clearly, educators can benefit from training in the effects of TBI on the school experience, and in specific strategies for addressing these students' academic, social, and behavioral needs. An increasing number of resources are available to educators to guide staff development efforts in ABI (see, for example, Begali, 1994; Blosser and DePompei, 1994; Savage & Wolcott, 1988; Tyler, 1990). In some areas, state-wide training efforts are being undertaken to increase knowledge and awareness of ABI in school settings (Todis & Glang, 1994; Lash & Scarpino, 1993; Pearson, 1994, Tyler, 1994).

In addition to gaining knowledge about working with students with ABI, educators may benefit from skill development in working collaboratively with the variety of disciplines represented on the school-based team (i.e.; family, related service providers, administrators) to provide educational services in general education settings. Training in creating effective parent-professional partnerships may be especially helpful. Unfortunately, parent-professional relationships can easily become adversarial because of the many stresses both family and school staff face in designing educational programs for students with ABI (Lash & Scarpino, 1993). As educators perceive parents as demanding and overbearing, and parents feel their child's unique needs are not being addressed, parents and teachers create roadblocks to effective service delivery. As Walker (1989) writes:

"A serious failure occurs in service delivery when the two most influential agents for change in the child's learning experience--parents and teachers--do not collaborate successfully in the planning and monitoring of the child's educational program. When this happens, the essential connection between home and school is lost. Unresolved conflict often leads to severed communication or adversarial encounters, and produces a great deal of stress for many parents and teachers. Ultimately, both parties may feel ineffective in their efforts on the child's behalf, and the student is cheated of the benefit of a coordinated learning experience." (p. 103)

The most effective approach to creating a successful transition back to school and an effective educational program will involve cooperative problem solving with the education and rehabilitation teams, family, and student.

Parents' role. Parents will be most successful in accessing effective educational services for their child when they: 1) are knowledgeable about their child's needs and the types of services that will benefit their child, 2) work collaboratively with school personnel to incorporate these services into the educational program, and 3) take time for themselves so that they can take on the time-consuming and stressful role of being their child's advocate. The final section of this chapter offers guidelines to help parents work with school personnel to create educational plans that meet their child's needs.

**Parent Skill #1: Get informed about services that will help your child and about your rights in accessing these services.**

Because most educators lack training in ABI, parents may be the most knowledgeable source of information about the effects of ABI and strategies for assisting students to be successful in school settings (DePompei & Blosser, 1987, 1994). Through their experiences in the rehabilitation setting, networking with other parents, and dealing with a variety of professionals in the field of brain injury, most parents learn a great deal about their child's needs and approaches that can be helpful. Parents may also have access to written materials and resources via state Head Injury Foundations, conferences, and other parent groups. Parents are also the most obvious source of information specific to their child's needs (DePompei & Blosser, 1991; Ylvisaker, Szekeres, Henry, Sullivan, & Wheeler, 1987). They can provide suggestions for behavioral, social, and cognitive interventions that are invaluable to the educational team.

Before a child returns to school following a brain injury, parents should insure that an inservice about ABI is provided to *all* staff (including non-educational staff such as janitors, coaches, and bus drivers). Possible sources for presenters include a neighboring district that has worked with students with ABI, a rehabilitation unit, the state Department of Education, or an intermediate education unit or agency. Parents and the student may also want to participate in the inservice, to discuss specifics about the student's injury and needs. As part of the inservice, parents should suggest that their child's school acquire print and

video resources about ABI so they can have resources for ideas and help as needed (see above sources).

*Jane's mother was closely involved in her daughter's hospital rehabilitation program and was impressed with Jane's ability to process new information when presented on a personal computer. When their small community asked how they could help after Jane was released from the hospital, her mother indicated that she would need a computer to do her homework. The community held a fund-raiser and purchased a computer and software for Jane. When school personnel expressed reservations about Jane's ability to use the computer, and about the value giving sophisticated equipment to a low-functioning third grader, Jane's mother invited several teachers to her home to see how Jane used the computer to practice math and reading.*

One of the most important roles for parents in developing the Individualized Education Plan (IEP) for their child is to share information about ABI with those responsible for providing the child's education. It is therefore critical for parents to become knowledgeable about the IEP process and other school procedures that must be followed in accessing special education services. Parents should familiarize themselves with their rights and responsibilities under IDEA (PL 101-476) by contacting the special education division of their state's Department of Education. Most states also have a parent education group about which the special education division should be knowledgeable (these groups have different names in each state, but their role is the same: to assist parents of students with disabilities in accessing appropriate educational services). In addition, because of the rapid changes associated with ABI, it is important that parents request frequent dates for their child's IEP (Savage & Mishkin, 1994). Unless parents participate fully in the IEP process, important strategies may not be included in the educational plan.

*A mother received notice that her daughter's IEP meeting was scheduled for a date two weeks away. Noting that only 20 minutes were allotted for the meeting, she asked whether she could reschedule when more time was available, since she would like to talk in depth about her daughter's goals, perhaps through a MAPS (a team-based problem-solving process)*



*planning session. The school staff responded that ideally they would hold such meetings for every special education student, but time did not permit this, so the staff would have the goals written prior to the meeting, and the mother could just sign off, as she had in previous years. The mother sought the advice of a parent advocacy group and learned that parents are entitled to be involved in goal setting, that the meeting must be scheduled at a time that is convenient for parents, and that parents are not obligated to sign an IEP just because the school staff is on a tight schedule.*

### **Parent Skill #2: Establish a collaborative relationship**

Becoming knowledgeable about effective strategies and services and the mechanisms for incorporating them into the IEP is necessary but does not guarantee that the desired student outcomes will be achieved. Parents must also advocate effectively and work collaboratively with the education team. For many parents, this is a difficult task.

There are a number of reasons why parent-professional relationships become unproductive. Turnbull and Turnbull (1986) list the following factors as contributing to adversarial relationships between parents of children with disabilities and educators: 1) poor communication skills; 2) unfavorable attitudes; 3) parental disinterest and lack of experience in dealing with medical and educational systems; 4) lack of coordination among various professionals and agencies working with families; 5) lack of professional training for dealing effectively with parent concerns and emotions; and 6) logistical problems in arranging contacts between parents and educators.

Improving parent-professional relationships may be less difficult than it seems. Walker (1989) offers three simple skills parents can use to foster collaboration between parents and professionals:

1. Take the perspective of the educator: understand the position taken by another and appreciate the good intentions that motivate behavior. It is especially important for parents to acknowledge that teachers and other school staff are already frustrated with the lack of time and resources to accomplish all they need to do.
2. Appreciate the steps taken that are helpful to parent and child: express appreciation for behaviors in others that are pleasing.



**3. Maintaining frequent contact: sustain communication between home and school through notes, phone calls, and personal visits.** Parents may want to find a key person at the school with whom they can communicate regularly. This might be a teacher, counselor, or nurse. Many parents also find it helpful to set up a daily journal in which they and their child's teachers can communicate back and forth from home and school, and to establish a regularly scheduled time to visit with their child's teacher about their child's progress (e.g., a weekly phone call on Friday afternoons, coffee together every other Wednesday morning).

Walker (1989) found that when parents and teachers both used these skills, there were increases in the number and length of parent-professional contacts, and the frequency with which individualized contacts occurred. Parent-professional contacts were also rated as more positive in tone, and there was an increase in positive perceptions toward collaboration in planning services for children.

#### **Parent Skill #3: Remember to take care of yourself**

It is important for parents to remember to take care of themselves as they deal with the stresses of working with educators to plan services for their child. If parents don't monitor their own stress and take steps to nurture themselves, they will be less effective advocates for their child (see Singer, this volume). For some parents, this may involve seeking the counsel of friends or a minister, while for others it may mean sticking to an exercise regime. For still other parents, taking time out for a shopping trip and lunch out may be helpful. It may also be important for parents to occasionally take a break from being an advocate and step back and re-group before beginning to advocate anew.

Sometimes parents are frustrated when they attempt to work collaboratively with school personnel but find that the school is unwilling to view parents as partners or team members. Parents may sense that school staff devalue their perceptions of their students' abilities and sees the parents' attempts to give input on school decisions and practices as interference with the educators' role.

Some parents respond by giving up and keeping quiet about their ideas for improving their child's educational program. Other parents develop personal

and practical skills for becoming effective advocates for their children. One mother tells of how this process unfolded for her:

I came from an alcoholic, abusive family. Before I was forced to begin advocating for my children eleven years ago, I had a high school education and I lacked the self confidence to confront people in authority about getting the services they were entitled to. I gradually became more empowered. But I've never done any of this alone. I've always taken a support person with me to meetings: a friend, my mother, and later, my attorney. My children have great school programs now, and I'm a different person. I'm starting law school next year.

### Conclusion

According to those with the most at stake in successful school experiences for students with ABI--parents, educators, and students-- the current educational service system is not meeting the complex needs of this group of students. To improve the way educational services are designed and implemented, educators and parents must work together to create innovative ways to serve children.

This chapter has focused primarily on what *parents* can do to improve their child's educational program: become knowledgeable about ABI and learn to work collaboratively with school personnel so that parents can effectively advocate for their child. The most compelling reason for parents to become effective advocates is the effect of positive parent-professional relationships on the child's school experiences. When teachers and parents work collaboratively, the child benefits.

The experiences of one adolescent serve as an example of the importance of parent advocacy. Following his severe brain injury, this high school senior was determined to carry on as if nothing had happened. Although he experience severe headaches and fatigue, he insisted on trying to maintain a full academic schedule. When he became exhausted and frustrated, he started cutting classes. In an interview several years following his injury, the young man talked about how he needed his mother to be a strong advocate because he was seen by school personnel as lacking credibility.

When you are by yourself you can't prove yourself and that's why I needed my mom so much. You know, she came in and said "Look? this is what's

going on. ...He's not skipping class because he's a slacker. He's skipping class because he doesn't understand. Because he can't understand. And because he is overwhelmed and it's snowballed and you need to give him some leeway on that." After my head injury...advocating for myself... was really really hard.

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**Tailoring Direct Instruction Techniques for Use  
with Elementary Students with Brain Injury**



## Tailoring Direct Instruction techniques for use with elementary students with brain injury

This article describes three case studies in which Direct Instruction techniques were used to teach students with brain injuries who participated in a 6-week tutoring program. The subjects were three children with closed head injuries who exhibited significant learning problems: two boys, ages 8 and 10, and a girl, age 6. After approximately 12 hourly instructional sessions, all three students made substantial academic progress as demonstrated by probe data collected in their targeted instructional areas (reading, language, math, and keyboarding). The gains were seen in both discrete and more complex skills, and some of the gains made represented new learning. In addition, the aggressive outbursts of one student were decreased substantially through use of a self-monitoring technique in the context of academic instruction. Results from these case studies suggest that Direct Instruction is a promising approach for teaching both academic and behavioral skills to students with TBI.

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**T**HE GROWING population of elementary school-aged children with traumatic brain injury (TBI) presents educators with a variety of new challenges. Numerous studies have documented a range of unique learning needs that tend to characterize this population of students with TBI.<sup>1-8</sup> For example, students with TBI may experience problems with attention and concentration, retention and retrieval of information, new learning, impulsivity, organization and planning, generalization of new skills, and thinking and reasoning.<sup>2,9</sup> Although students with TBI may share certain learning needs in common with one another, it is important to acknowledge the heterogeneity across and variability within these students.<sup>10</sup> That is, no two students with TBI present the same learning profile, and moreover a particular student's learning rate and ability vary widely from day to day (ie, the Swiss cheese phenomenon).

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Despite the abundance of literature documenting the challenges involved in meeting these students' diverse learning needs, there has been little empirical research on the effectiveness of particular instructional strategies that would help guide teachers in designing instructional programs for their students with TBI.<sup>5</sup> In one of the only published studies evaluating cognitive intervention,<sup>11</sup> students made measurable gains in adaptive behavior but few improvements in cognitive functioning.

There exists, however, a substantial body of research regarding instruction of students with other types of learning problems that can be drawn upon in designing effective instructional interventions for students with TBI. Direct Instruction<sup>12</sup> is one of the most promising approaches for teaching academic skills to students with TBI, partly because of its capacity to be tailored to meet individual learning needs. Originally developed as a model for teaching economically disadvantaged students, Direct Instruction programs have been used successfully over the past 25 years with a wide range of learners with special learning needs.<sup>13</sup> Researchers have reported the effectiveness of Direct Instruction techniques in teaching reading, language, and math skills to children with learning disabilities<sup>14,15</sup> and moderate to severe retardation<sup>16</sup> (see Gersten<sup>17</sup> for a review of research on Direct Instruction applications with special populations).

#### UNIQUE FEATURES

The foundation of the direct instruction approach is simple. All students can learn if instructional communications are presented logically, unambiguously, and clearly. Like most behavioral approaches, direct instruction uses task analysis, modeling and shaping, reinforcement of appropriate responses, and continuous assessment to ensure student

learning. Direct Instruction also includes the following unique features, however:

- All component skills are pretaught.
- Students are taught general case problem-solving strategies.<sup>18</sup> A range of carefully selected examples is used to promote generalization of strategies to untaught examples. Examples are sequenced so that they build on prior learning.
- Instructional wording is consistent and clear to decrease student confusion.
- Systematic corrections are built into instruction to provide immediate practice with difficult tasks.
- Sufficient practice is provided to ensure mastery at each step in the learning process.
- Cumulative review of all skills ensures integration of new skills with previously learned information.

The design and presentation features of the Direct Instruction approach specifically address many of the learning characteristics typical of these students. The box, "Learning Characteristics of Children with TBI and Relevant Direct Instruction Features," presents the most common learning problems associated with TBI and the components of the Direct Instruction approach that address those problems.

Direct Instruction curricula are carefully sequenced so that instruction on new skills builds on skills previously learned. This characteristic of Direct Instruction has led some to believe mistakenly that this approach is overly rigid and therefore unadaptable for meeting individual needs. This assumption is faulty, however, because it is indeed possible to target and teach only those lessons or segments of lessons that are appropriate for a particular student. Teachers who are thoroughly trained in Direct Instruction techniques use these programs in just such a diagnostic-prescriptive fashion. That is, the

well beyond the most rapid period of spontaneous recovery, and none of the children had any history of documented learning difficulties before their injury.

After an initial evaluation, the teacher began individualized instruction with each student. Students were tutored two to three times per week for 6 weeks at the tutoring site.

## STUDY 1

### Subject

The subject in study 1, Thomas, was an 8-year-old boy who sustained a closed head injury when struck by a motor vehicle 15 months before participating in the tutoring program. The accident resulted in a basilar skull fracture with subdural hematoma and intraparenchymal hemorrhage. Thomas was comatose for approximately 3 weeks. Cognitive deficits included severe problems with attention, memory, and visual-motor abilities. On the Wechsler Intelligence Scale for Children-Revised,<sup>20</sup> Thomas achieved a full scale IQ score of 81 (verbal score, 81; performance score, 84).

At the time of his participation in the study, Thomas had just completed the second grade. He received special education services for math and spent the rest of the day in a second-grade classroom.

### Procedure

Thomas was tutored twice a week over a 6-week period (13 sessions total). Before the baseline phase, the teacher evaluated Thomas and met with his parents and classroom teacher. On the basis of his educational goals, her assessment, and these discussions, the teacher targeted three instructional areas: reasoning skills, math story problems, and addition and subtraction math facts (ie, adding and subtracting the numbers 1 through 10).

The baseline phase consisted of a series of probes in each instructional area. During each baseline session, Thomas completed a worksheet with five written story problems, a 1-minute timing on math facts, and five verbally presented questions involving deductive reasoning skills. Sample items from each of the probes appear in the box, "Probes for Subject 1."

### Instruction

After establishing baseline performance, the teacher began instruction in each academic area. Instructional order was varied during each session.

The teacher taught Thomas by using the relevant strands from two instructional programs: Corrective Reading Comprehension Level A<sup>21</sup> and Corrective Mathematics.<sup>22</sup> Thus rather than teaching complete lessons each day, the teacher selected only segments of lessons designed to remediate Thomas's specific academic weaknesses. The three strands used to teach Thomas are described briefly below.

#### Probes for Subject 1

1. *Math story problem:* Mike builds dog houses for a job. He built 8 dog houses last week. Then he built 17 more dog houses this week. He sold 5 dog houses over the weekend. Mike earns money delivering papers too. He delivers papers 7 days a week. How many dog houses does Mike have built to sell? (20)
2. *Math facts:* The probe sheet consisted of a random selection of addition and subtraction facts (eg, 7+4, 10-8, and 12-9) presented vertically.
3. *Reasoning skills:* All reptiles are cold blooded. A lizard is a reptile. So a lizard is cold blooded.



### Reasoning Skills

Students with TBI often experience deficits in higher-order skills such as reasoning and judgment. The Deductions Strand from the corrective reading comprehension series concentrates on teaching a variety of reasoning skills central to solving a wide range of problems. One of the component skills taught involves making logical deductions from information presented. Although the ability to make logical deductions is not in itself an indicator of a student's overall reasoning or problem-solving skills, it is an important component skill of a complex set of reasoning abilities.

As determined by his baseline performance, Thomas needed to begin instruction with the most basic form of deductions: those involving a rule that applies to all members of a class. With this form of deduction, the student learns to apply a rule to a specific member of the class. For example, in lesson 2, the wording is as follows:

1. Listen to this rule. *All birds have feathers.*  
Say that.  
*All birds have feathers.*
2. What do *all* birds have?  
*Feathers.*
3. Say the rule again.  
*All birds have feathers.*
  1. Listen. Robins are birds. Say that.  
*Robins are birds.*
  5. Listen. *All birds have feathers.* Robins are birds. So, robins . . .  
*. . . have feathers*

As the lessons progress, the teacher provides less structure for each deductive statement. Deductions involving *no* (eg, "No reptiles fly. A snake is a reptile. So a snake . . .") and *some* (eg, "Some animals fly. Henry has an animal. Does it fly?") are introduced once deductions with *all* are mastered. In this study, Thomas practiced all three types of deductions.

### Math Story Problems

The Story Problems Strand of the Corrective Mathematics program teaches a precise strategy for solving math story problems. Students learn to discriminate problem types and to attend to only relevant information in the problem. In working with Thomas, the teacher modified the story problem strategy taught in the Corrective Math program as follows:

**When working a story problem, you:**

1. First read the question at the end.
2. Underline what you're being asked to find out.
3. Go to the beginning of the problem and read it.
4. As you read, underline words that are the *same* as the words in the question.
5. Figure out if you should add up or take away.
6. Do it.
7. Write out the answer.

Thomas was taught to solve both addition and subtraction story problems that contained a variety of distracting information (see the above probe example for a sample problem type).

### Math Facts

Math facts are taught as members of a series in the Facts Strand of the Corrective Math program. For example, the program presents  $10+1$ ,  $10+2$ ,  $10+3$ ,  $10+4$ , and  $10+5$  as a series. In this way, students learn the relationship between the various facts. Once the student achieves proficiency with the fact series, facts are practiced individually in both written and verbal contexts.

Over the course of the tutoring program, Thomas practiced five addition fact families (5+ series and 9+ series) and two subtraction fact families (9- series and 5- series)

### Data collection

The teacher collected probe data twice during each session (before and after the lesson). Each day, she collected and scored Thomas' worksheets after he had completed

them. A research assistant independently scored 24 of Thomas' worksheets (8 from each instructional area). Interobserver agreement on these measures averaged 99% (166 agreements out of 168 responses).

### *Experimental design*

A multiple baseline across content area was used to evaluate the effectiveness of the tutoring program. Instruction was introduced sequentially in each area once baseline performance stabilized.

### **Results**

Fig 1 depicts Thomas' performance in each of the three instructional areas. Once instruction was begun, Thomas made immediate and substantial improvement in all three areas.

#### *Reasoning skills*

During the baseline phase, Thomas averaged 6.7% correct on verbally presented deductions. His responses indicated a complete lack of understanding of the reasoning process and often included totally irrelevant information. A sample of Thomas' responses (in italics) to the deductive statements presented during baseline follows:

Some ice cream has nuts. Chocolate is one ice cream. So . . . *lick 'em.*

Some mountains have tall peaks. Mt Jefferson is a mountain. So Mt Jefferson . . . *doesn't move.*

As soon as instruction began, Thomas' performance improved dramatically. He no longer guessed or offered irrelevant responses. Thomas' performance maintained at the 80% to 100% level throughout the instructional period, an acceptable instructional range for a student with learning problems.<sup>25</sup>

#### *Story problems*

Thomas' performance on story problems followed a similar pattern. As soon as the

teacher began instruction in the story problem strategy, his accuracy increased significantly, from an average of 11.4% correct in baseline to an average of 91.3% correct during instruction.

Because all steps in the problem-solving strategy are critical to its successful implementation, it was important for Thomas to learn to follow all steps in the problem-solving strategy. Initially, the teacher guided him through each of the steps, providing corrective feedback as necessary. A key component of the instructional process was to fade these teacher prompts.

#### *Math facts*

During the baseline phase, Thomas completed an average of 6.0 facts per minute. His rate increased to an average of 11.5 facts per minute during the instructional period. Although this represents a substantial increase over baseline performance, it is still considerably lower than what an average third-grade student could be expected to complete. Thomas' slow performance primarily can be attributed to his poor fine motor skills. If he had given the answers orally rather than in writing, his performance would probably have increased more dramatically.

### **STUDY 2**

#### **Subject**

Jill, the subject for study 2, was a 6-year-old girl who was injured in a motor vehicle/pedestrian accident 12 months before the study began. As a result of the accident, she sustained a severe brain injury with evidence of a left temporoparietal contusion. She was comatose for several months and remained hospitalized for approximately 4 months. As a result of her injury, Jill had severe deficits in expressive language and mild deficits in re-

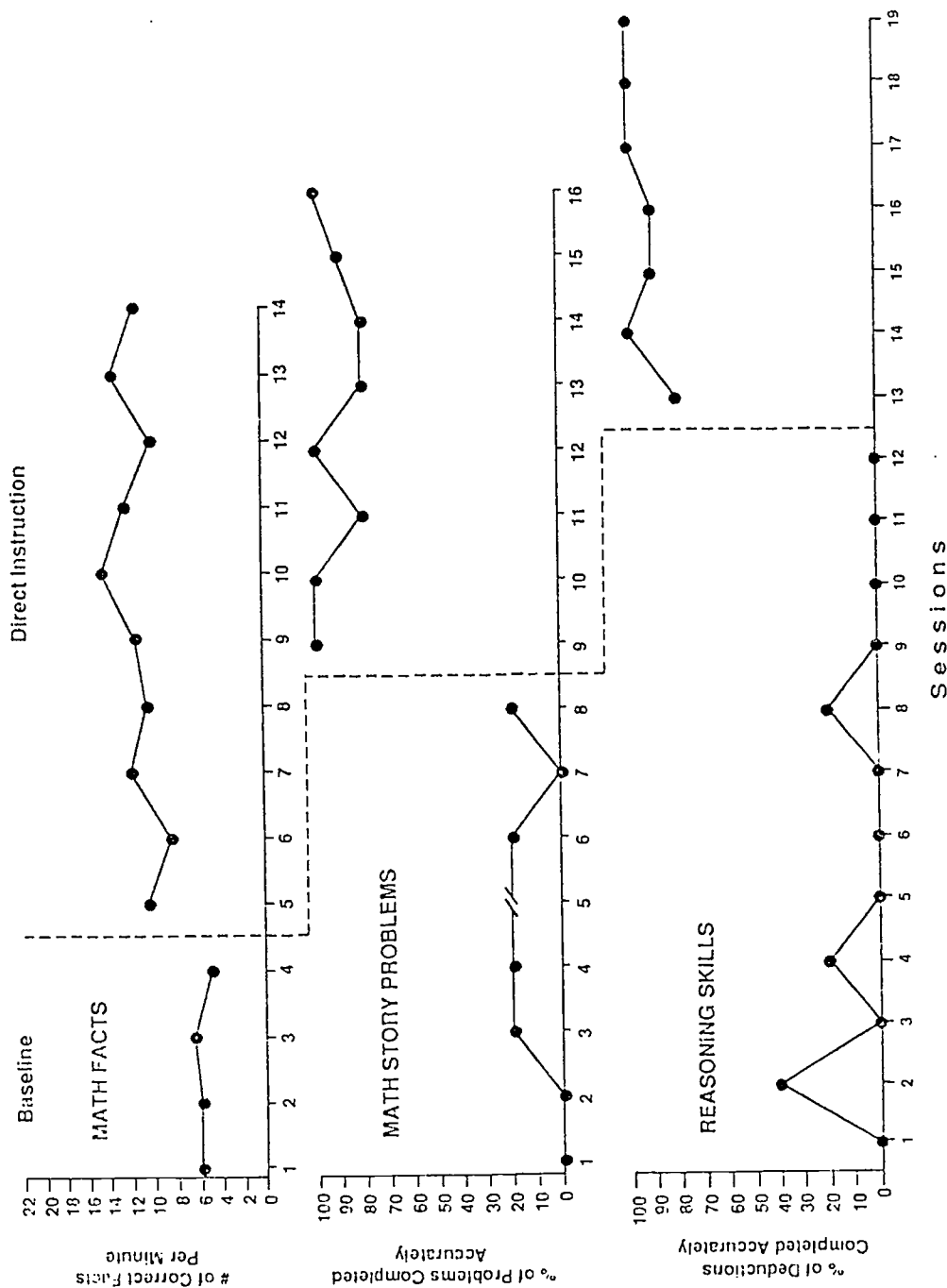


Fig. 1. Effectiveness of direct instruction tutoring in math facts, math story problems, and reasoning skills (Thomas).

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ceptive language and visual-motor ability. Four months after her injury, a neuropsychological assessment revealed that because of her extremely limited vocalizations it was difficult to assess Jill's language abilities accurately on any standardized measures. Although her performance on the Peabody Picture Vocabulary Test-Revised (a measure of verbal receptive abilities) was at the 3-year 9-month level, she showed little spontaneous appropriate single-word speech.

Before beginning the study, Jill was tested with the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) and the Woodcock-Johnson Tests of Achievement (reading subtests only). On the WPPSI, Jill obtained a full-scale IQ score of 65 (verbal IQ score, 64; performance IQ score, 73). Jill's verbal comprehension and expression were noted to be particularly weak. On the Vocabulary, Similarities, and Comprehension subtests, she achieved scaled scores of 4 (second percentile), 4 (second percentile), and 1 (< first percentile), respectively, all in the severely impaired range. As at the previous testing, Jill's verbal expressive skills continued to be quite low: spontaneous vocalizations were limited to two- and three-word phrases. Unfortunately, additional testing information was not available for Jill in the area of language abilities. Her reading performance on the Woodcock-Johnson was at the kindergarten level.

When the study began, Jill had just completed kindergarten. She had attended a special education classroom and also received speech, physical, and occupational therapies through the school district.

#### Procedure

Jill was tutored two to three times per week (12 sessions total). The teacher targeted beginning language and reading skills for instruction. During baseline, Jill was probed on a list of visually presented sounds and a series

of simple sentences that she was to repeat (eg, "The big bed was soft." "The fish swims in the water").

#### Instruction

The teacher began instruction after baseline performance stabilized. The order of instructional presentation varied each day.

Jill was taught beginning language and reading skills by means of *Distar Language I* and *Reading Mastery I*.<sup>25</sup> *Distar Language I*, designed for preschool and kindergarten students, teaches a variety of skills essential for successful functioning in the classroom. In this program, students learn prepositions, classification skills, common information (eg, days of the week and seasons), and other skills that provide the foundation for classroom instruction. The *Reading Mastery I* program is designed to teach beginning reading skills to nonreaders. It includes prereading exercises, beginning decoding skills, and initial work with comprehension skills. Like other Direct Instruction programs, the program carefully sequences the skills taught so that students learn successfully. For example, highly similar sounds (eg, *b* and *d*) are separated by many days of instruction to avoid confusion. The sequence of skills is controlled so that students master the skills they need for subsequent, more complicated tasks. The instructional strands from each program taught to Jill are described below.

#### Sentence Repetition

The ability to repeat statements is an important component skill of reading comprehension; once students can remember and repeat a simple statement, they are much better prepared to understand written text. In some cases, students with TBI may have difficulty mastering this skill because of any one of a number of problems associated with TBI (eg, dysarthria or auditory perceptual deficits), and instructional strategies must be al-



tered. For most students, however, the ability to recall and repeat short statements is an important component skill of reading comprehension.

The Identity Statements strand in *Distar Language I* was used to teach Jill to repeat statements. This strand uses pictures to teach students to make complete statements. Students learn first to identify the object in the picture and then to form a complete sentence about it.

#### Sound Identification

In *Reading Mastery I*, students are initially taught to decode words by using a sounding-out strategy. By means of the Sound Identification strand, Jill was taught to identify individual sounds in isolation.

#### Data collection

Probe data were collected before and after each lesson on sound identification and statement repetition. The teacher wrote down Jill's response to each item and recorded whether it was correct or incorrect. A research assistant independently collected data on 16 of the 46 probes. Interobserver agreement averaged 100% (200 agreements out of 200 responses).

#### Experimental design

An AB design was used to determine the effectiveness of the instructional program on Jill's reading and language skills. Such a design is seriously limited by its lack of experimental control. Therefore, results derived from it may be interpreted as only suggestive.

#### Results

Jill's probe performance is depicted in Fig 2. Substantial improvement over baseline levels is apparent in both statement repetition and sound identification. The stability of her performance during the baseline phase suggests that changes during the instructional

period were not due to spontaneous recovery.

#### Statement repetition

On the statement repetition probes during baseline, Jill was able to repeat an average of 47.9% of the words presented. Most of the probe statements consisted of five to six words, but Jill was only able to repeat an average of three words. For example, when presented with "This tree is tall and green," she repeated, "Tall green." When the teacher stated, "She is riding a bicycle," Jill repeated, "Riding bicycle." It should be noted that this type of language pattern was consistent with Jill's conversational style. During the instructional period, her performance improved to an average of 72.8%. She repeated most words in all probe statements and often repeated statements verbatim. Anecdotal reports from Jill's teacher suggested that her spontaneous speech also increased in complexity during the instructional phase.

#### Sound identification

As a nonreader, Jill was unable to identify any of the 20 sounds presented to her during baseline. With instruction, her performance improved rapidly to an average of 6.2 (31%) correct sounds. Most importantly, she remembered sounds from one session to the next, even though there were generally 2 to 3 days between sessions.

#### STUDY 3

The final case study differed from studies 1 and 2 in that it emphasized instruction in a positive behavior rather than specific academic skills. In this study, the intervention taught a behavioral self-management strategy by using a Direct Instruction approach.<sup>26</sup> The same principles used to teach academic skills were utilized in providing instruction in a

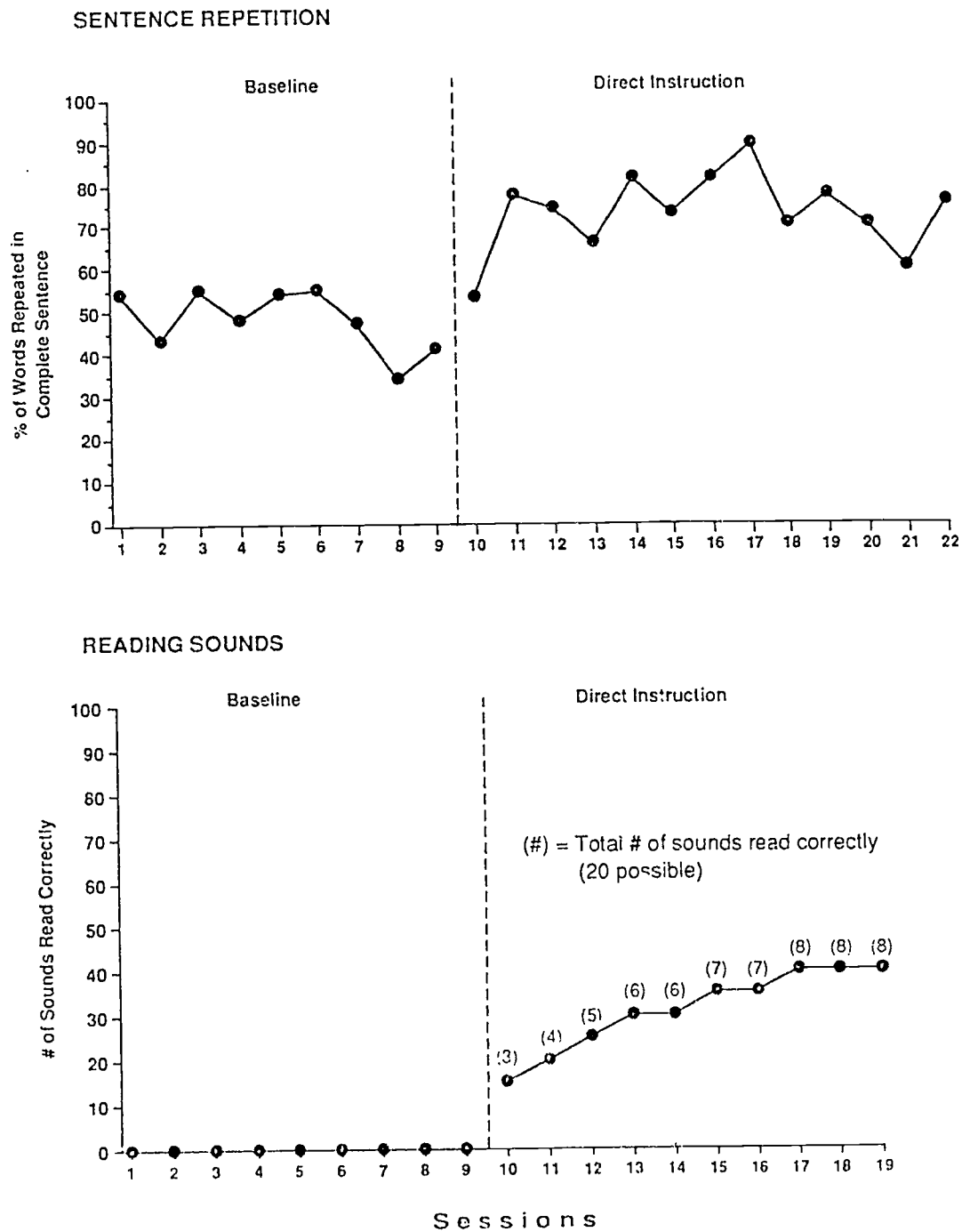


Fig 2. Effectiveness of direct instruction tutoring in language and reading (11)

positive behavior; that is, a generalizable strategy was taught by means of rapid instructional pacing, a wide range of examples, immediate corrections, and positive feedback.

The subject for study 3, Paul, was taught a strategy for controlling his aggressive behavior in the context of instruction in academic areas. Although the effectiveness of behavioral strategies with children with TBI has not been carefully documented, recent studies have reported on the utility of these techniques with adults who have experienced brain injury.<sup>27-30</sup>

### Subject

Paul was a 10-year-old boy who had been injured in a motor vehicle/pedestrian accident 19 months before the study. In the accident, Paul suffered a severe brain injury with brain stem contusion and was comatose for approximately 3 months. Neuropsychological testing approximately 1 year postinjury revealed a significant visual-spatial deficit, poor fine motor control, and slow and dysarthric speech. He scored in the low-average range on a measure of intelligence and two to three grade levels below his expected grade level on academic measures.

During the previous school year, Paul had been placed in a self-contained special education classroom. His behavior prevented him from being mainstreamed during the day. His teacher reported that Paul often became physically aggressive and required a time-out room. A one-to-one aide assisted Paul at all times throughout the day.

Before beginning tutoring, Paul was assessed with the Wechsler Intelligence Scale for Children-Revised<sup>31</sup> and the Woodcock-Johnson Tests of Achievement.<sup>32</sup> Initially, Paul was cooperative with the testing. When the test items became difficult, however, Paul became frustrated and aggressive, at one point attempting to strike the examiner. Test-

ing was attempted on several occasions with the same result. Because of his disruptive behavior, the examiner was unable to complete the testing. Thus an accurate assessment of Paul's skills was not obtained. Decreasing Paul's aggressive behavior became a primary goal of his tutoring program. From discussions with his parents and classroom teacher, the teacher targeted spelling, math facts, and keyboarding as the academic contexts for teaching the behavioral strategy.

### Procedure

Paul was tutored for 12 total sessions. In each subject area Paul was assessed, and instructional tasks were selected (ie, unknown spelling words, math facts, and keyboarding strokes).

The teacher used common Direct Instruction strategies to teach each content area (eg, tasks were practiced until mastery criteria were met, corrective feedback was supplied immediately after an error, and so forth). During the baseline phase, the teacher established a behavioral system to reward Paul for appropriate behavior. When he followed the teacher's directions and responded correctly, the teacher awarded points. If he earned 10 points, Paul could play a game on the computer for 5 minutes.

Our initial assessment showed that Paul was cooperative as long as he was successful with a task. He became aggressive when the task became more difficult and he required corrective feedback. During baseline, the teacher collected data on Paul's response to corrective feedback in all three target areas. Each time Paul was corrected, the teacher recorded whether or not he remained on task (defined as not engaging in the following behaviors: looking away from the instruction materials, shoving his work away, hitting the materials or furniture, striking the teacher, or attempting to leave the room).



### *Intervention*

Once Paul's baseline behavior pattern stabilized in the first instructional area (math facts), the teacher taught him a self-management strategy for dealing with his frustration. Whenever he made an error, Paul was to do the following:

1. Stop.
2. Look at the problem.
3. Listen to the answer.
4. Try it again.

Paul practiced this strategy throughout the math facts lesson. The teacher provided corrective feedback when he forgot one step in the strategy and praised accurate use of the self-management technique.

The point system established during baseline was continued during this phase. To determine the degree to which Paul would generalize the self-management strategy to the other subject areas, the intervention was practiced only during the math facts instructional time. That is, Paul was not reminded to use the strategy during either spelling or key-boarding. He did earn points for accurate work and appropriate behavior during those times, however.

### *Data collection*

The teacher collected data on Paul's response to corrective feedback in all three target areas. Each time Paul was corrected, the teacher recorded whether or not he remained on task. An independent observer concurrently collected data on three of the instructional sessions. Reliability was calculated by dividing the number of agreements by the number of agreements plus disagreements. Interobserver reliability averaged 92% (65 agreements out of 71 responses).

### *Experimental design*

An AB design with generalization probes was utilized to assess the effectiveness of the self-management strategy.

### *Results*

Fig 5 shows that the point system alone did not significantly affect Paul's aggressive behavior. Once he was taught the self-management strategy, there was a clear increase in Paul's on-task behavior after academic correction in math facts. This pattern was also apparent in the other two instructional areas, where the strategy was not introduced. Generalization probes indicated that Paul used the self-management strategy without any prompts when he faced frustration in key-boarding and spelling. He demonstrated continued use of the strategy during a follow-up probe at 3 months.

During baseline, Paul became easily frustrated when he had difficulty with an instructional task. For example, on the first day of instruction he worked appropriately with the teacher for approximately 5 minutes. When he made an error, the teacher's correction set off a chain of aggressive behavior. Paul pushed the book he was working from, hit the book, and then struck the teacher and tried to grab her earring. When she prevented him from doing this, he attempted to leave the room.

By the end of the tutoring program, Paul worked productively for 30 minutes at a time. When he made an error, he would often verbalize some or all of the self-management strategy (eg, "I stop, look, listen, and try again"). When he was tired and wanted a break, he asked the teacher appropriately if they could stop working for a while. This pattern of behavior occurred in all three subject areas.

### *DISCUSSION*

The results of these case studies show that the direct instruction approach can be effective in teaching both academic and behavioral skills to children with brain injuries. Af-

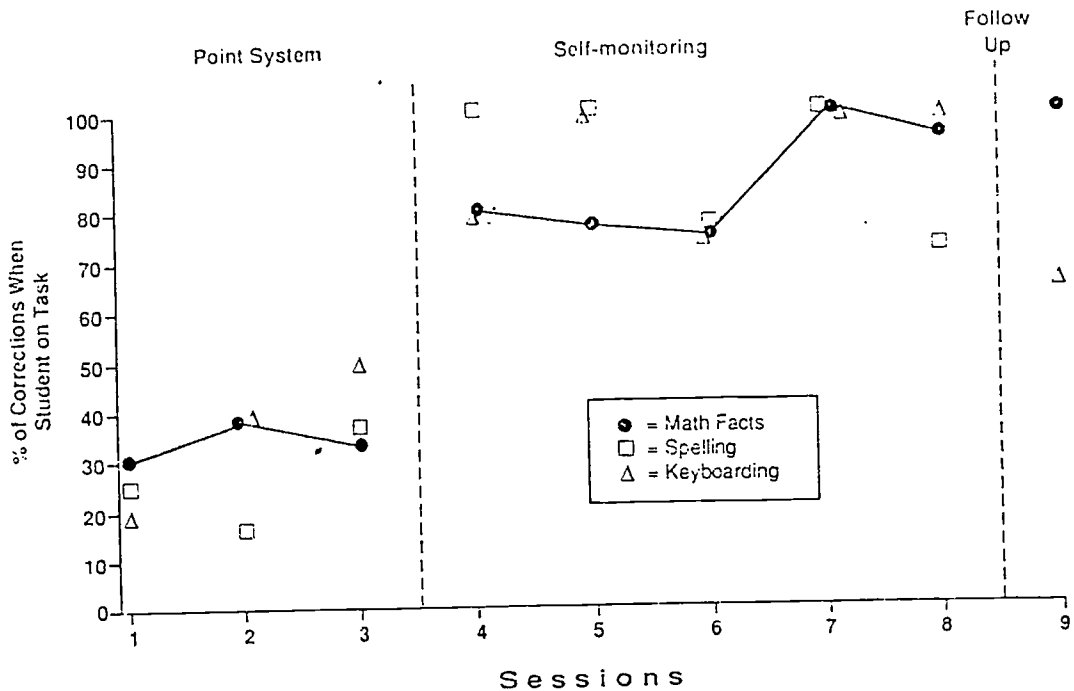


Fig 3. Effectiveness of self-monitoring strategy in maintaining on-task behavior (Paul).

ter approximately 12 hourly instructional sessions, all three students made substantial academic progress in their targeted instructional areas. The gains were seen in both discrete and more complex skills. For example, Jill improved in reading sounds and repeating simple sentences, and Thomas learned to work math story problems, a skill involving more abstract reasoning.

The use of a Direct Instruction approach to teach a self-management technique produced a notable increase in Paul's rate of academic engagement. After learning a self-monitoring technique in the context of academic instruction, Paul's aggressive outbursts decreased substantially in response to error correction. In addition, Paul's use of the strategy maintained 3 months after the tutoring program ended. Although learning and memory deficits may pose difficulties when one is imple-

menting behavioral strategies with students with TBI,<sup>42</sup> in this case a fairly straightforward behavioral technique taught with Direct Instruction was effective.

Through participation in the tutoring program, all three students regained skills lost after their injury. In addition, some of the gains made represented new learning; Jill, for example, had never had reading instruction before the study, and Paul was learning keyboarding for the first time. It is important to note that these gains were made more than 1 year postinjury in each case, suggesting that the gains were not simply a result of spontaneous recovery.

It may be argued that the effects demonstrated in these case studies can be attributed to factors other than the instructional methodology implemented. Students may have improved over the course of the tutoring pro-

gram because of practice effects or the individualized attention provided by the tutor, although these explanations appear unlikely given the sustained low performance during baseline and the pronounced increases after intervention. Because the students received individualized attention from the instructor during all phases of the study, including baseline, their improvements may not be attributed to instructional interaction alone. Moreover, research with other populations suggests that the design and presentation variables of Direct Instruction are functionally related to student academic gains.<sup>52-56</sup> Further research is needed to document more fully the effectiveness of these instructional design and presentation variables with children with TBI. Of specific interest is a more fine-grained analysis of the relative effectiveness of cumulative and integrated review, rapid pacing, general case programming, and skills sequencing. Research on the effectiveness of the direct instruction approach with adolescents and young adults would also be enlightening.

Another limitation of this study is the lack of documentation of generalization of effects to classroom performance. The focus of this study was to evaluate the effectiveness of a Direct Instruction approach in an individualized context. Logistical constraints rendered it infeasible for us to assess the degree to which the students' gains transferred to classroom behavior. Investigation of the functional application of this approach to classroom performance should be a focus of future evaluation efforts.

Although the Direct Instruction approach appears promising as a means of meeting the needs of students with TBI, it is not without its flaws. For example, extensive training is required to implement the model effectively. In a year-long evaluation of a Direct Instruction implementation effort, Gersten et al.<sup>6</sup> found that teachers took a full 8 months to

master all aspects of the Direct Instruction teaching approach. Gersten et al.<sup>6</sup> reported that students of teachers who did not fully master the techniques made significantly less progress on measures of achievement. Thus a teacher who simply picks up the materials and begins teaching students will have far less success than a teacher who is well trained.

A thorough knowledge of the Direct Instruction model is particularly important given the heterogeneity across and variability within students with TBI. Because Direct Instruction curricula follow a careful skills sequence, a teacher working with this population must be able to tailor Direct Instruction materials rather than simply use them in a packaged fashion.

The Direct Instruction approach typically involves the placing of students into instructional groups, a practice recommended by program authors. However, because students with TBI often show very uneven and unpredictable progress in learning,<sup>37</sup> group placement may be problematic. Often these students will demonstrate great variability in their learning rates and patterns. In addition, because of their delayed processing time, students with TBI may have difficulty keeping up with the pace of group-delivered instruction. Therefore, caution must be used to ensure that the students' unique learning needs will be met if they are taught in a group setting.

These case studies suggest that the use of Direct Instruction teaching techniques resulted in meaningful student progress over a 6-week period. As the population of young children with TBI increases each year, so does the demand for effective instructional approaches. Although there are many potentially promising approaches developed for other populations that could be modified for use with students with TBI, the case studies reported here indicate that the Direct Instruction model may be particularly useful in ad-



Addressing the diverse needs of students with TBI. As one such promising approach, Direct

Instruction clearly warrants continued investigation.

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**Training an Interdisciplinary Team  
in Communication and Decision-Making Skills**

*The use of interdisciplinary teams to address human service delivery issues is becoming increasingly common. Complicated problems require the expertise of a variety of specialists from different disciplines, and in need specialization brings with it a heightened need for interdisciplinary collaboration. While team meetings are expected to serve as the vehicle for successful collaboration among professionals, three barriers often stand in the way of effective team interactions: disorganization, misunderstandings, and problem-solving difficulties. These problems suggest a need for interventions aimed at improving team communication and decision-making processes, as well as a need for methods to observe and evaluate the effects of such interventions on a team's functioning. The purpose of this research was twofold: First, we sought to investigate the effects of an intervention that differentially targeted and trained three sets of group communication and decision-making skills aimed at addressing the three barriers mentioned above. A second goal was to develop new methods of observation that would overcome several serious limitations which have characterized the bulk of existing team intervention research. An interdisciplinary rehabilitation clinic's staff served as the subject of the study. Using a multiple baseline design across categories of behaviors, the effects of a three-part intervention on the team's day-to-day meeting behavior was assessed. While there was substantial variability and overlap in much of the data, videotaped observations revealed that following each training session, there were modest increases in the average frequency of use of most targeted behaviors. Social validation data indicated that team members found the training to be both useful and enjoyable. Implications for future research are discussed.*

## TRAINING AN INTERDISCIPLINARY TEAM IN COMMUNICATION AND DECISION-MAKING SKILLS

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Interdisciplinary team practice has been gaining momentum in a wide variety of settings including hospitals, rehabilitation facilities, mental health centers, nursing homes, hospices, drug/alcohol

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treatment programs, and schools (Gaitz, 1987; Lecca & McNeil, 1985). Contributing to its rising prevalence is the fact that as medical technology advances and knowledge about human service delivery and educational issues burgeons, it becomes impossible for a single professional or discipline to possess all of the requisite information/skills to adequately meet the needs of a given client or student (Gaitz, 1987; Giangreco, 1986; Lecca & McNeil, 1985). Complex problems often require the expertise of specialists from a variety of disciplines, and increased specialization brings with it a heightened need for interdisciplinary collaboration in order to avoid fragmented service delivery (Rothberg, 1985).

Interdisciplinary team meetings are expected to serve as the vehicle for this collaboration among professionals, and effective teamwork is vital to that collaboration. Figure 1 presents a conceptual framework for viewing team functioning. Essentially, an effective team meeting may be thought of as comprising at least three elements: organized presentation of material and use of time, interactive communication among members resulting in mutual understanding of group goals and decisions, and sufficient involvement of group members in constructive problem-solving efforts.

Unfortunately, however, simply bringing together a group of professionals does not necessarily ensure that they will function effectively as a team or make appropriate decisions. Effective teamwork does not occur automatically. Many problems related to the interdisciplinary team interaction process itself have been cited with respect to teams and work groups that run the gamut of service delivery settings, purposes, and compositions. Also shown in Figure 1, these process-related difficulties tend to cluster into three categories:

1. *Disorganization:* Interdisciplinary teams frequently operate in the absence of any well-defined procedures. The purpose and outcomes of meetings are often unclear to the members, and information may not be presented in a logical fashion (Bailey, 1984; Hackman & Walton, 1984).

2. *Miscommunication and misunderstanding:* Because interdisciplinary teams are by definition composed of individuals with diverse professional perspectives and languages, they are particularly prone to problems that stem from heterogeneity (Randolph &

Blackburn, 1989). These problems include misunderstandings arising from members' varied use and interpretation of each others' jargon, conflicts and "turfism" (Golightly, 1987; McGonigel & Garland, 1988). Good communication skills would be helpful in preventing or alleviating such problems; unfortunately, members of interdisciplinary teams often lack training and proficiency in such skills (Moore, Fifield, Spira, & Scarlato, 1989).

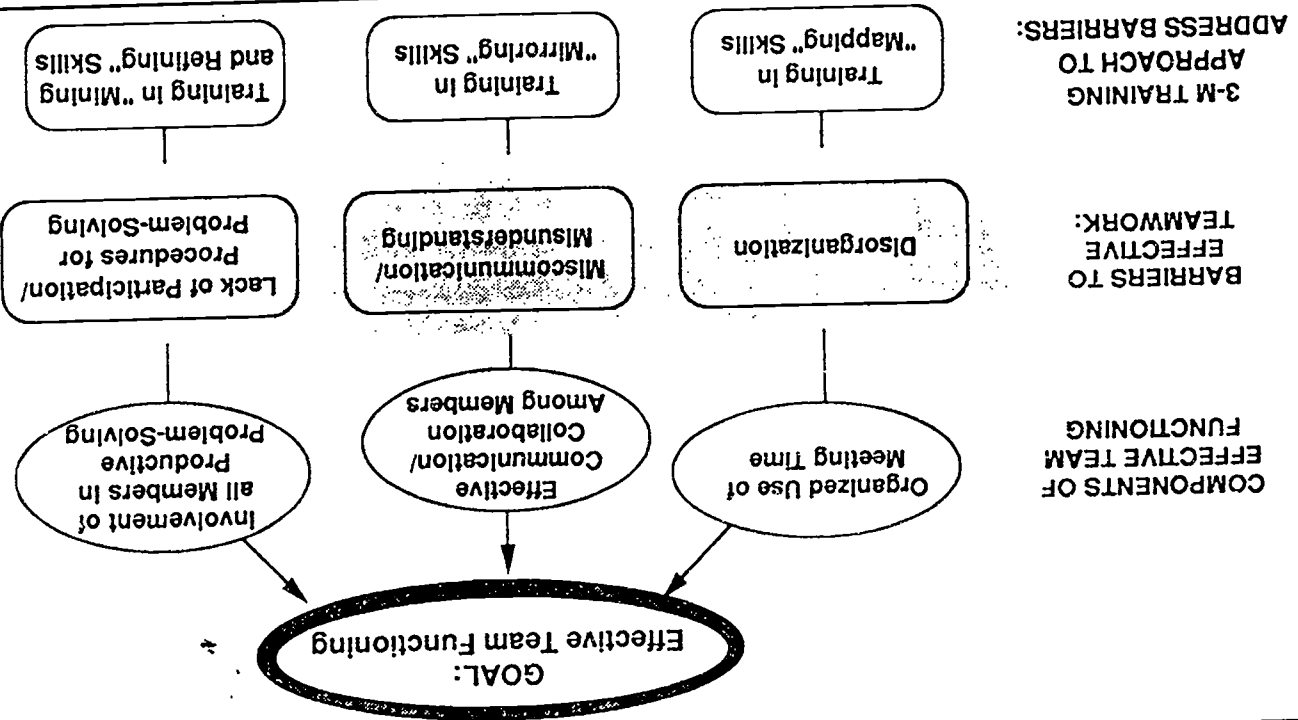
3. *Inadequate participation in/procedures for problem solving:* To achieve the goal of bringing a variety of perspectives to bear on a particular problem, a team meeting would ideally be a situation in which every member's input is readily available and used. Unfortunately, members do not always participate optimally in group discussions; some are too reserved, while others may dominate the meeting by speaking disproportionately or inappropriately (Bailey, 1984). In addition, groups frequently lack a structured approach for group problem solving, making it difficult if not impossible for the group to address issues in anything but a haphazard fashion (Bulger, 1985; Moore et al., 1989).

All of the problems listed above concern the *internal processes* associated with a team's collaborative efforts to accomplish its goals. While effective team processes are not necessarily ends in themselves, they are the means to achieve effective service delivery to clients. Previous research has shown that problems in a team's interactional processes can hinder its accomplishment of its goals (Johnson & Johnson, 1987; Robbins, 1989).

Due to the relationship between the effectiveness of team processes and the quality of team outcomes, a line of research has emerged that aims to identify ways to improve team functioning. A wide variety of team-based interventions have been developed and evaluated, and Figure 1 outlines the training model employed and evaluated by this study. Before detailing the procedures of this study, however, we turn next to a discussion of previous team intervention research.

The difficulties associated with measuring the effects of team interventions have resulted in serious limitations in the research done to date in this area. For example, many of the experimental group studies of team development interventions lack validity

Figure 1: A Conceptual Framework and Training Model for Addressing Common Barriers to Effective Team Functioning



because the groups consist of college students or other "artificial" populations (Schweiger & Sandberg, 1989). Conversely, studies of intact work groups operating in real-world settings have tended to lack experimental control due to the difficulty in arranging suitable randomized control groups in actual organizational settings (Spencer & Coye, 1988).

Furthermore, measurement of team communication processes has proven equally challenging, and most existing studies of team development interventions have not employed measures of observable behavior change in team members. Thus, while many team development interventions result in improvements in member satisfaction, one is usually left to wonder whether or not those interventions actually resulted in any behavioral change in the teams' day-to-day operations.

The purpose of this study was to investigate the behavioral effects of a team training model (depicted in Figure 1) that differentially targeted three categories of group communication and decision-making skills. The three skill areas related specifically to the three barriers to team functioning discussed earlier. This effort was intended to overcome the limitations described above by employing a controlled research design using an intact service delivery team as the subject of study. Moreover, the study operationally defined key communication and decision-making skills in such a way as to allow systematic assessment of the effects of the training on the team's day-to-day meeting behavior.

## METHOD

### SUBJECTS AND SETTING

The subjects in this study were 25 staff members of a rehabilitation clinic specializing in the treatment of individuals with chronic pain. This clinic is located in a Pacific Northwest community of 150,000. Its staff consisted of 11 administrative members and 14 treatment professionals from a variety of disciplines including medicine, psychology, social work, physical therapy, and occu-

pational therapy. There were 9 males and 16 females on the staff. The mean age was 37 years, with a range of 21 to 48 years. The entire staff participated in the training workshops, and the average number of staff members present during observed meetings was 9 (range = 5-17).

Ideally, a group under study would consist of stable membership. However, the staff of this treatment center met in different configurations depending on which client or issue was being discussed, making it impossible to target and observe one stable staff subgroup over time. The fact that members' attendance varied somewhat according to the purpose of a particular meeting created an instability in the unit of analysis that posed measurement challenges. And yet, since this kind of fluctuation in team membership is typical of so many intact human service delivery teams operating in real-world settings, it was seen as worthy of accommodation in the study's design. The primary challenge was to determine whether the intervention was powerful enough to produce changes in behavior over and above whatever variability was inherent to the team's fluctuating composition.

This study's accommodation of fluctuating team membership was accomplished in two ways. First, by delivering the intervention to the entire staff instead of only to certain staff members, it was ensured that no matter what the configuration of individuals present at any given staff meeting, the members had received equal exposure to the intervention. Second, the meeting itself (i.e., the summative rates of target behaviors that occurred in each one) as opposed to a particular configuration of team members, served as the unit of analysis. Measuring summative rates of target behaviors per 5-minute intervals during meetings allowed for the examination of the intervention's behavioral effects on the center's meetings. Given that the baseline occurrences of behavior remained fairly constant in level and variability, changes seen in targeted (but not control) behaviors following intervention could be attributed to intervention. In other words, this system of measurement enabled assessment of whether or not any changes in the rehabilitation center's overall meeting behavior (regardless of member configuration) occurred as a function of intervention.



To render the observations as representative as possible of interdisciplinary team experiences, only those meetings in which at least three disciplines were represented were observed. Therefore, meetings consisting solely of administrative support personnel, for example, were excluded because the homogeneity of membership in such meetings is not typical of interdisciplinary team meetings.

### DESIGN

Single subject research designs are well suited to the study of team-focused interventions because they provide a means of exercising experimental control while observing only a few or even a single team in its natural context (Kazdin & Tuma, 1982; Komaki & Zlotnick, 1985). This study employed a multiple baseline design across behaviors to investigate the effects of a behavioral skills training program for interdisciplinary team members. The rehabilitation staff's team meetings served as the unit of analysis. The effects of the three-part intervention targeting specific communication and decision-making skills were assessed by collecting data continuously on all of the targeted behaviors at once and intervening in staggered fashion on one specific set of behaviors at a time. Thus there were four phases of the study (three of them corresponding to the titles of the training components): baseline, mapping, mirroring, and mining and refining. In each phase the nontargeted behaviors served as experimental controls for the targeted ones. The Baseline condition refers to observed occurrences of targeted behaviors prior to intervention upon them.

### PROCEDURES

#### ACCESS TO SETTING AND DATA COLLECTION PROCEDURES

The team under study was recruited via a flier describing the training program and offering it free of charge to interdisciplinary teams. Upon obtaining written consent from all staff members of

the clinic to participate in the study, each participant completed an intake questionnaire which solicited demographics of the participants and information about the nature and content of the center's team meetings.

The data collection process included conducting direct observations of videotaped team meetings and administering a social validation questionnaire following each of three training sessions. Both are described further in the Measures section.

To collect videotaped observations of team meetings, a 1/2" VHS video camera was positioned on a tripod in a corner of the treatment center's conference room which provided an adequate view of the team members and the immediate surroundings. The camera's built-in timer function allowed the running time to be displayed along the bottom of the screen. One of the staff members was instructed in how to operate the video equipment and was responsible for recording the meetings. Five videotaped observations of team meetings were conducted prior to any training. There were three training workshops; between each one five videotaped observations were made. Thus the total number of meetings videotaped was 20, and the total span of time covered by the study was roughly 3 months.

### TRAINING CONTENT

All staff members participated in three 2-hour on-site training workshops that were held 3 to 4 weeks apart. Each of the three workshops was conducted by the author and was designed to teach a set of skills relevant to overcoming each of the three team process barriers mentioned earlier:

- "3-M" Team Training Approach
1. Disorganization → Mapping skills workshop
  2. Miscommunication → Mirroring skills workshop
  3. Problem-solving difficulties → Mining and refining skills workshop

Each workshop targeted specific skills and employed teaching methods that have already in the literature been demonstrated or

posited to be important elements of an effective work group. Following are brief rationales for and identification of the sets of skills targeted in the three training sessions, called respectively mapping, mirroring, and mining and refining. A more detailed description of training procedures and skill definitions may be found in Cooley (1991).

#### Session One: Mapping

This session focused on the development of skills that help a group track or map where it's going, where it is, and where it's been, thus reducing disorganization. Groups easily get sidetracked because of the natural tendency for individual members to be thinking different things at different times. Even when a group uses a written agenda, members may get lost in discussions and fail to progress in a logical fashion from one topic to the next. The three communication skills targeted in this session were previewing what will occur next in the meeting (Sugai & Colvin, 1990), consensus testing to determine group agreements (Schmuck & Runkel, 1985), and summarizing remarks (Schmuck & Runkel, 1985).

#### Session Two: Mirroring

This session targeted four skills designed to foster improved communication and understanding among team members. The mirroring analogy alludes to the right and responsibility of each team member to "see and be seen, to hear and be heard" during team meetings. Given the heterogeneity of interdisciplinary team membership, the potential for miscommunication to occur is great. Skills targeted in this workshop consisted of both listening and sending skills, including paraphrasing other members' remarks (Johnson & Johnson, 1987), probing for clarification of another's remarks (Bormann & Bormann, 1988), pinpointing specific behaviors and examples (Schmuck & Runkel, 1985), and personalizing via the use of "I statements" when describing a problem's impact (Johnson & Johnson, 1987).

#### Session Three: Mining and Refining

The third session was designed to teach processes and skills that facilitate more involvement and creativity on the part of members during problem solving, since a lack of participation may result in fewer contributions and options being considered. The mining and refining image refers to ways that a group can "mine" its raw material more effectively by eliciting every member's involvement and input, and then "refine" that material by using a structured problem-solving sequence. This session emphasized the importance of equalizing member participation and focused primarily on the introduction and practice of a structured problem-solving sequence called "SYNERGY." The sequence employed in this intervention drew upon a variety of group problem-solving strategies identified in the literature, all of which consist of a sequence similar to the following: Problem definition, problem analysis, generation of alternatives, selection of a solution, evaluation and follow-up (Aubrey & Felkins, 1988; Fox, 1987; Schmuck & Runkel, 1985; Ulschak, Nathanson, & Gillan, 1981). The SYNERGY acronym served as a mnemonic device for the seven problem-solving steps for facilitating broader involvement and creativity that were taught in the training session (See Cooley, 1991).

#### TRAINING FORMAT

All three of the workshops employed the following behavioral training procedures (Porras & Anderson, 1981; Zamanou & Glaser, 1989) for teaching team members the targeted skills: conceptual presentation, modeling, observational training using examples from their own videotaped meetings, written practice and role playing.

#### MEASURES

##### VIDEOTAPED OBSERVATIONS AND RELIABILITY CHECKS

The investigator observed videotapes of the team meetings and coded the frequency with which the various targeted behaviors



occurred during every 5-minute interval of the meeting. That is, meetings were observed in their entirety—not sampled. Targeted skills were operationally defined, and a scoring grid was developed that listed the target behaviors along one dimension and 5-minute meeting intervals along the other. Tally marks were made to indicate the frequency with which the behaviors occurred in each meeting interval.

A mean rate (frequency per 5-minute interval) of each of the targeted behaviors was calculated for every observed meeting, regardless of meeting length or the number of members present, thus allowing comparison of skill use across different kinds of meetings. This observational procedure was followed for all of the targeted skills except the use of the problem-solving sequence.

The team's use of the problem-solving sequence was expressed as a percentage of the seven steps used during a given meeting as opposed to a rate per interval. For example, a meeting in which the group engaged in three of the seven steps would receive a score of .43, while a meeting in which six of the seven steps were used would receive a score of .86.

Also measured was the extent to which the participation during a given meeting was evenly distributed among the members. In arriving at a means of measuring this, the concepts of market share and industry concentration were borrowed from the field of economics. A statistic known as the Herfindahl Index (Martin, 1988) is used to compute the density of competition within an industry. That is, firms within a particular industry each possess a certain proportion or share of the market. By squaring the proportion of the market that each firm holds and then summing these figures, one arrives at a figure between 0 and 1 that serves as an index of industry concentration. The lower the index, the more evenly distributed the shares of the market.

Group participation can be usefully viewed in the same way by substituting the notion of "airtime" for market share. That is, each member, whenever she or he speaks, uses up a certain proportion of the available airtime. By squaring each person's total proportion of airtime and adding these figures, one arrives at a figure, here referred to as the participation index, which measures the distribu-

tion of participation among members during the meeting. Participation indexes were calculated for all of the videotaped meetings to assess the effects of the intervention on the degree to which participation was equalized among the members. The procedure for obtaining these indexes is further detailed in Cooley (1991).

Twenty-five percent of the videotapes were randomly selected and coded by a second observer who was blind to the phases of the study. Interobserver reliability was calculated by dividing the total number of agreements by the total number of agreements plus disagreements across all behaviors observed.

#### SATISFACTION MEASURES

Social validation data were collected via a one-page questionnaire that assessed participants' satisfaction with each of the three training workshops. Following each training workshop, participants responded anonymously to six items asking them to rate various aspects of the training using a 5-point, Likert-type scale (1 = *very disappointing*, 3 = *acceptable*, 5 = *extremely well done*). These items included: organization of the workshop, content, skill practice, handouts, presenter's delivery, and overall quality/usefulness. Open-ended written comments regarding the strengths and weaknesses of each session were solicited as well.

## RESULTS

#### SKILL USE

Figure 2 depicts the degree to which team members used the various communication and decision-making skills in their meetings before and after each of the three training workshops, as well as the extent to which the distribution of meeting participation varied over the course of the entire study. Table 1 reports the pre- and postintervention means and standard deviations for these same skills.

TABLE 1: Pre- and Postintervention Means and Standard Deviations for Targeted Skills

Skills	Pretraining		Post-training	
	$\bar{X}$	SD	$\bar{X}$	SD
Mapping				
Previewing	.71	.30	1.21	.72
Summarizing	.44	.31	.73	.37
Consensus testing	.22	.13	.31	.37
Mirroring				
Paraphrasing	.47	.25	1.21	.46
Pinpointing	.31	.20	.83	.52
Personalizing	.34	.39	.54	.44
Probing	.40	.18	.79	.49
Mining and refining				
Percentage of steps	.57	.20	.63	.21
Distribution of participation	.26	.10	.20	.06
	.29 <sup>a</sup>	.10 <sup>a</sup>	.20 <sup>b</sup>	.06 <sup>b</sup>

a. Premirroring.  
b. Postmirroring.

points. Moreover, effects appear to be inconsistent across both behaviors and time. In light of these facts, the results need to be interpreted cautiously and viewed as merely suggestive at best. Nevertheless, there appear to be some changes occurring as a function of intervention, and these will be described next for each category of behavior.

While quite variable, the degree to which members initially used all three skills of previewing, summarizing, and consensus testing was relatively low during the baseline phase. After the 2-hour mapping workshop, there appeared to be somewhat of an increase in both the level and variability of members' use of all three of these targeted skills over subsequent meetings (see Figure 2 and Table 1). For example, the mean frequency of previewing per 5-minute interval across meetings increased from .71 during baseline to 1.21 for the 15 meetings following training. In other words, prior to the intervention, any one member of the team would preview an average of once every 7 minutes, whereas in postintervention meetings, the mean rate increased to roughly once every 4 minutes. The standard deviation of all three skills also increased following

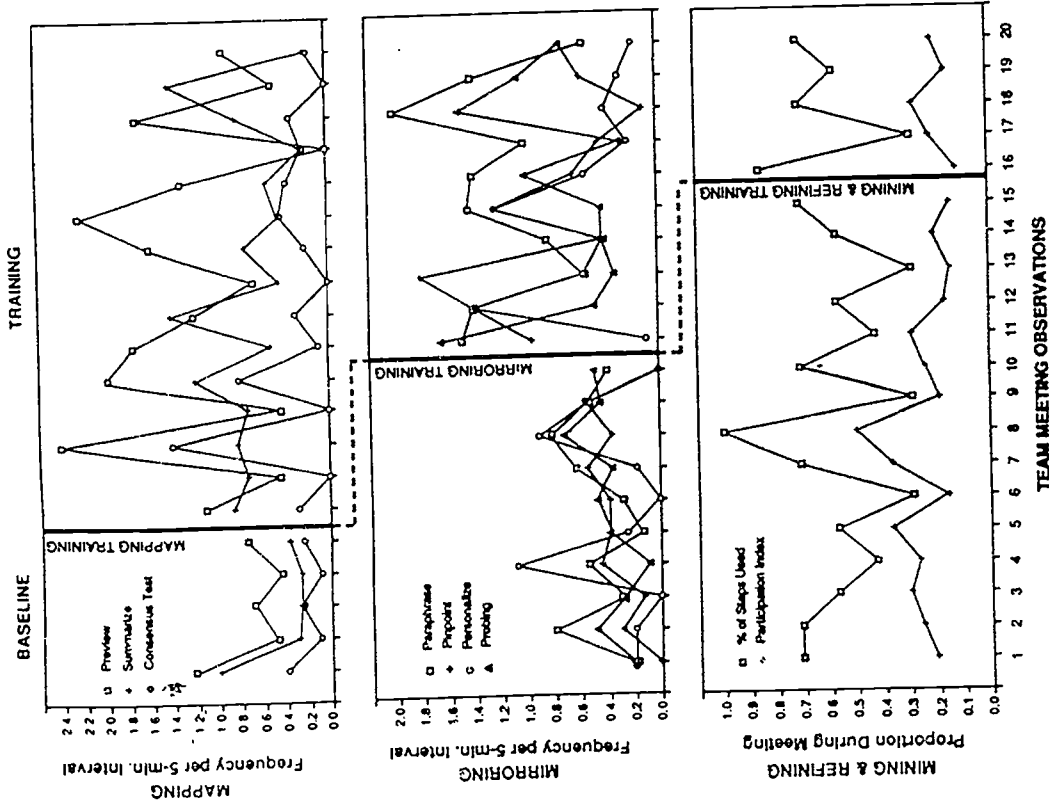


Figure 2: Behaviors Observed During Team Meetings

The data for many of the measures were highly variable, and there was considerable overlap between pre- and post-training data

training (see Table 1) reflecting the fact that after training there were more high data points in spite of the considerable overlap between phases.

The baseline rates for all four mirroring skills were also quite variable, although there was no change in overall trend during this phase. Mean baseline rates for the four skills were .47, .31, .34 and .40 for paraphrasing, pinpointing, personalizing, and probing, respectively (see Table 1 and Figure 2). Subsequent to the mirroring workshop, the mean rates for the four skills increased to 1.21, .83, .54, and .79, and the variability also increased. For both the mapping and mirroring sets of skills, initial effects were modest and unsustained over time.

The third category of behaviors appear to have been unaffected by the third workshop which was designed to affect them. That is, the group's use of the seven problem-solving steps varied widely throughout the study, and there was no change in overall level following intervention. Thus the intervention appeared to have no effect on the group's use of the steps in the problem-solving sequence.

One unanticipated result was that following the second workshop (mirroring), there appeared a slight decrease in trend of the participation indexes (see Figure 2), suggesting that participation became somewhat more evenly distributed following the mirroring workshop. As can be seen from the numbers with superscripts in Table 1, the premirroring mean participation index was .29 as compared with a postmirroring mean of .20. Following the mining and refining workshop, the mean participation index remained unchanged at .20. Thus it appears that the mirroring portion of the intervention had a small effect on the degree to which members shared participation in the meeting, while the mining and refining workshop had no additional effect on the distribution of participation.

#### RELIABILITY

Interobserver reliability checks were made on five randomly selected videotaped observations (25% of all observations). Reli-

TABLE 2: Means and Standard Deviations of Workshop Evaluation Items<sup>a</sup>

		Mapping (n = 25)	Mirroring (n = 24)	Mining and Refining (n = 22)
Organization	$\bar{X}$	4.16	3.92	4.45
	<i>SD</i>	0.78	0.56	0.50
Content	$\bar{X}$	3.80	3.86	4.23
	<i>SD</i>	0.49	0.66	0.73
Skill practice	$\bar{X}$	3.76	3.68	4.36
	<i>SD</i>	0.86	0.88	0.57
Handouts	$\bar{X}$	3.92	4.25	4.41
	<i>SD</i>	0.69	0.66	0.49
Presenter's delivery	$\bar{X}$	4.12	4.12	4.33
	<i>SD</i>	0.59	0.52	0.47
Workshop overall	$\bar{X}$	3.92	3.81	4.33
	<i>SD</i>	0.69	0.47	0.56
Grand mean	$\bar{X}$	3.95	3.94	4.35
	<i>SD</i>	0.15	0.19	0.07

a. 1 = very disappointing; 5 = extremely well done.

ability was calculated by dividing the number of agreements by the number of agreements plus disagreements on all communication and decision-making code categories and averaged 92% across the five observations (range = 86% to 96%).

#### PERCEPTIONS OF THE INTERVENTION

Means and standard deviations for workshop evaluation questionnaire items are reported in Table 2. All questionnaire items asked participants to rate the particular workshop along several dimensions using a 5-point Likert-type scale (1 = *very disappointing*, 3 = *acceptable*, 5 = *extremely well done*). In addition to the quantitative items, there were two open-ended items soliciting likes, dislikes, and suggestions regarding the workshop.

The grand mean for all mapping workshop items was 3.95; for the mirroring workshop it was 3.94. The mining and refining workshop received the highest ratings of the three, with a grand mean of 4.35. Means on the individual items for all sessions ranged from 3.68 to 4.45. Open-ended comments indicated that partici-

participants found the workshops relevant, useful, and well-organized, but that they would have liked more time for the sessions. Several people commented on the usefulness of the SYNERGY problem-solving process in particular.

#### DISCUSSION

This study investigated the effects of training an interdisciplinary team in communication and decision-making skills. Using a multiple baseline design across behaviors within one service delivery team, the degree to which a three-part intervention affected the group's behavior in applied work situations was assessed. In addition, subjective measures were used to ascertain participants' satisfaction with the intervention.

Participants' subjective evaluations of the three workshops indicated that they found all three to be useful, enjoyable, and practical, and that they considered the targeted skills to be relevant and worth integrating into their day-to-day work routines. The observations of team meeting behavior yielded data that was highly variable and in which there was considerable overlap between phases, indicating that the intervention did not powerfully affect team dynamics. While many of the targeted skills showed initial "spikes" following intervention in the desired directions, they also returned to baseline levels later in the study. Such results are not surprising given the difficulties associated with achieving transfer of skill use from the training environment to the work environment. Effects of training are often minimal and transient unless some type of ongoing consequences are provided for the newly acquired behaviors (Komaki, Heinzmann, & Lawson, 1980; Quilitch, 1975). Exactly what those consequences would need to be in the case of the skills targeted herein would be a possible avenue for further research. Interpretation of these results is complex, however, given the realities of studying a team with fluctuating membership in its natural context. "Clean" results (whereby the use of targeted skills is absent during baseline and frequent following training) are highly unlikely in a study such as this one because all of the targeted skills

occurred to some extent during baseline observations. That is, at least some team members had these skills in their behavioral repertoire from the start. Increases in skill use following intervention could indicate either that some team members acquired new skills and began implementing them in team meetings or that the workshops functioned to call attention to skills already in members' repertoires and enabled members to use them more often as needed.

The latter interpretation may shed some light on the meaning of the observed increases in variability of skill use. While some variability surely stemmed from varying team composition, fluctuating membership alone would not account for observed increases in variability seen only in targeted behaviors following intervention. Instead, variability in skill use may serve as an indicator of a particular skill's consistency of usefulness. Rather than being uniformly useful in all situations and types of meetings, certain targeted skills may be more appropriate in some situations than in others. One interpretation of the observed increases in variability for two of the skill sets, then, is that the first two workshops perhaps served to add to the team members' repertoire of skills and/or to enhance their ability to draw more often on this repertoire as the need for certain skills arose.

A critical difficulty in interpreting this or any other observational data on communication skill use during meetings is that it is as yet unknown what constitutes an optimal level of skill usage. Clearly, all of the targeted skills are relatively low-rate behaviors even when used optimally. For example, if summarizing were to occur any more than once every couple of minutes, the result would be a meeting in which the group spent almost all of its time summarizing its progress while making none! Yet, if summarizing did not occur at all, the group might never succeed in deriving any conclusions from their discussions. Thus a potential avenue of future research might be to attempt to identify optimal skill use under various circumstances.

Similar questions remain unanswered with respect to distribution of participation as were evident for communication skill use. It is generally assumed that fairly equal participation among members will optimize team performance. Different distributions of



participation may, however, be more appropriate under certain circumstances. The fact is that no one yet knows what constitutes a particularly high or low distribution of participation or under what circumstances a particular participation index is optimal.

Despite its limitations and modest results, the present investigation contributes to the research on interdisciplinary teams in a number of important ways. The problem of studying team interactions and interventions designed to affect them has always been a thorny one. It has in the past been assumed that a necessary tradeoff exists between scientific rigor and relevance of findings to intact, functioning teams, for the difficulties associated with performing randomized group studies using real-world teams are virtually insurmountable. Yet, by applying the single subject research methodology to the study of an intact team functioning in the community, this study did not sacrifice experimental control as many other studies of real-world teams have. Moreover, the current study identified and operationally defined specific, measurable behaviors as targets of intervention and observation. This kind of approach would seem to be at the heart of any empirical endeavor, yet it has been lacking in much of the existing team-related research. The coding scheme developed for tracking the use of targeted skills using the team meeting as the unit of analysis may be a useful contribution, as may be the creation of a new method for indexing the extent to which participation is distributed among team members during meetings.

A critical area unaddressed by this study and many others is the domain of team outcomes. Only when we are better able to define an interdisciplinary team's success or failure in accomplishing its purpose(s) can we most usefully employ methods such as those developed in this study to delineate the factors that contribute to team success or failure. When team outcomes can be better defined, future research may usefully link team processes to outcomes by asking such questions as: Under what circumstances are particular communication and decision-making behaviors associated with positive and negative team outcomes? What effect does the distribution of participation among team members have on team outcomes? If participation is skewed as opposed to equalized among

members, are there particular configurations of participation that contribute toward more positive outcomes (i.e., whose participation matters most?). Is there a predictable relationship between team composition and type of outcome achieved?

Once team outcomes can be reliably defined and evaluated, the relationships between particular outcomes and the processes used to achieve them may be further clarified. The means of observation and intervention employed by this study may prove useful along the way toward that end.

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Membership in cohesive groups has a powerful influence on individual behaviors such as adherence and conformity. Although the psychological and physiological benefits of exercise have been well documented, individual adherence has proven to be problematic. Given that exercise classes are minimal groups at best, the purpose of the present study was to determine whether measures of cohesion secured during the early stages of group development could be used to predict subsequent drop-out behavior. In Study 1, participants in university fitness classes were administered the Group Environment Questionnaire after the third week of a 13-week session. Adherence behavior, as measured by absenteeism, was monitored for 4 weeks and used to form two extreme groups—regular attenders and drop-outs. The regular attenders ( $n = 20$ ) were those individuals who attended at least 66% of the monitored classes; drop-outs ( $n = 17$ ) were those individuals who were absent for all classes in the monitored period. Discriminant function analysis showed that regular attenders held significantly greater perceptions of task cohesion than the drop-outs. Study 2 was a replication with exercise participants in private fitness clubs. A protocol identical to Study 1 was used to measure cohesion, operationalize adherence and analyze the data. Perceptions of cohesion again were a reliable predictor of adherence in the private club setting. However, it was measures of social cohesion that significantly discriminated between regular attenders ( $n = 30$ ) and drop-outs ( $n = 16$ ). The results were discussed in terms of their implications for (a) the dynamics of minimal groups, (b) the generality of the cohesion-adherence relationship in exercise groups, (c) the importance of considering the setting, and (d) health behavior change intervention programs.

## GROUP COHESION EFFECTS IN EXERCISE CLASSES

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In the group dynamics literature, there has been considerable discussion surrounding the question of what constitutes a group. Zander (1982) highlighted the issues involved when he pointed out

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**Using Direct Instruction with Brain Injured Students**



# Using Direct Instruction with Brain Injured Students

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Because of significant advances in medical technology over the past fifteen years, the lives of children and youth who formerly died of traumatic brain injury (TBI) are now being saved in increasing numbers. Each year, approximately 165,000 children and youth require hospitalization for brain injuries sustained in motor vehicle accidents, falls, sports, and physical abuse (Bush, 1986). Of these children, 20,000 will be left with long-lasting alterations in social, behavioral, physical, and cognitive functioning (Kalsbeek, McLaurin, & Harris, 1980; Rosen & Gerring, 1986). The incidence rates for the most severe traumatic brain injuries are higher than those for spinal cord injury, multiple sclerosis, cerebral palsy, and muscular dystrophy combined (Kurtze, 1982).

The growing population of school-aged children with TBI presents teachers with a variety of new challenges. Students with TBI have unique learning characteristics, including problems with concentration, memory, new learning, organization and planning, generalization of new skills, and thinking and reasoning (Savage, 1988).

Direct Instruction (Engelmann & Carnine, 1982) is one of the most promising approaches for teaching academic skills to students with TBI. The design and presentation features of Direct Instruction programs specifically address the learning characteristics of these

students. Table 1 presents the most common learning problems associated with TBI and the components of the Direct Instruction approach which address those problems.

This article describes two case studies in which Direct Instruction programs were used to teach a variety of skills to students with brain injuries. The purpose of the studies was to evaluate the effectiveness of Direct Instruction techniques in teaching academic skills to students with severe brain injuries.

## Case Studies

The case studies described here were conducted as part of a federally funded project designed to evaluate intervention strategies for families of children with brain injury and the schools that serve these children ("Home/School Support for Families of Children with Traumatic Brain Injury," Singer & Glang, 1989). As part of this project, a free tutoring program was offered to any student with a documented brain injury (i.e., hospitalization following traumatic brain injury with ensuing coma of at least 24 hours). All students who participated were at least *one year post injury*, well beyond the most rapid period of "spontaneous recovery." Instruction was provided by a certified special education teacher who had experience working with brain-injured learners.

Following an initial evaluation, the teacher began individualized instruction with each student. Students were tutored 2-3 times per week for 6 weeks.

Table 1. Learning Characteristics of Children with TBI and Relevant Direct Instruction Features.

Learning Characteristic	Direct Instruction Feature
Concentration	Rapid instructional pacing. Instructional tasks broken down into components. Student engagement maintained through high response and success rates.
Memory	Sufficient practice and review.
New learning	Skills sequenced to build on previous learning. Generalizable strategies. Sufficient practice. Effective use of corrective feedback.
Organization and planning	Problem-solving strategies. Consistent, structured instruction.
Generalization	General-case programming.
Thinking and reasoning	Instruction in generalizable learning and reasoning strategies in addition to instruction in content.

# DI with Brain Injured Students—Continued

## Study 1

### Subject

Jill, the subject for study 1, was a 6 year old girl who was injured in a motor vehicle/pedestrian accident 12 months before the study began. As a result of the accident, she sustained a severe brain injury, with evidence of a left temporoparietal contusion. She was comatose for several months, and remained hospitalized for approximately four months.

Prior to beginning the study, Jill was tested using the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) and the Woodcock-Johnson Tests of Achievement (reading subtests only). On the WPPSI, Jill obtained a full scale IQ score of 65 (Verbal IQ score: 64, Performance IQ score: 73). Her reading performance on the Woodcock-Johnson was at the kindergarten level.

When the study began, Jill had just completed kindergarten. She had attended a special education classroom and also received speech, physical, and occupational therapies through the school district.

### Procedure

Jill was tutored two to three times per week (12 sessions total). The teacher targeted beginning language and reading skills for instruction. During baseline, Jill was probed on: (1) a list of visually presented sounds, and (2) a series of simple sentences that she was to repeat (e.g. "The big bed was soft," "The fish swims in the water.")

### Instruction

The teacher began instruction after baseline performance stabilized. Jill was taught beginning language and reading skills using *DISTAR Language 1* (Engelmann & Osborn, 1976) and *Reading Mastery 1* (Engelmann & Bruner, 1983). The order of instructional presentation varied each day.

**Sentence repetition.** The "Identity Statements" strand in *DISTAR Language 1* was used to teach Jill to repeat statements. This skill provides the foundation for other comprehension skills and must be mastered before students can be expected to understand written text.

**Sound identification.** Using the sound identification strand, Jill was taught to identify individual sounds in isolation.

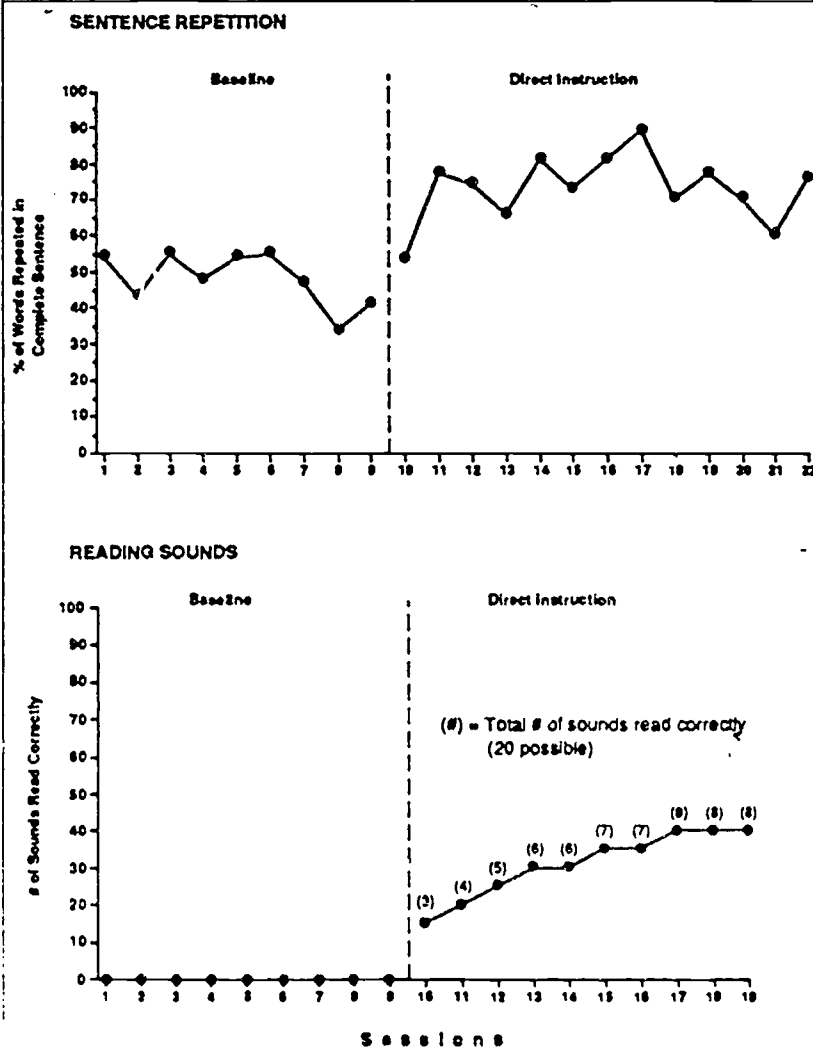
### Data collection

Probe data was collected before and after each lesson on sound identification and statement repetition. The teacher wrote down Jill's response to each item and recorded whether it was correct or incorrect. A research assistant independently collected data on 16 of the 46 probes. Interobserver agreement averaged 100% (200 agreements out of 200 responses).

### Experimental design

An AB design was used to determine the effectiveness of the instructional program on Jill's reading and language skills.

Figure 1. Effectiveness of Direct Instruction Tutoring in Language and Reading (Jill).



## Results

Jill's probe performance is depicted in Figure 1. Significant improvement over baseline levels is apparent in both statement repetition and sound identification.

**Statement repetition.** On the statement repetition probes during baseline, Jill was able to repeat an average of 47.9% of the words presented. Most of the probe statements consisted of 5-6 words; but Jill was only able to repeat an average of 3 words. For example, when presented with "This tree is tall and green," she repeated, "tall green." When the teacher stated, "She is riding a bicycle," Jill repeated, "riding bicycle." It should be noted that this type of language pattern was consistent with Jill's conversational style. During the instructional period, her performance improved to an average of 72.8%. She repeated most words in all probe statements, and often repeated statements verbatim. Anecdotal reports from Jill's teacher suggested that her spontaneous speech also increased in complexity during the instructional phase.

**Sound identification.** As a non-reader, Jill was unable to identify any of the 20 sounds presented to her during baseline. With instruction, her performance improved rapidly to an average of 6.2 (31%) correct sounds. Most importantly, she remembered sounds from one session to the next, although there were generally 2-3 days between sessions.

## Study 2

### Subject

The subject in Study 2, Thomas, was an 8 year old boy who sustained a closed head injury when struck by a motor vehicle 15 months prior to participating in the tutoring program. The accident resulted in a severe skull fracture with subdural hematoma and intraparenchymal hemorrhage. Thomas was comatose for approximately 3 weeks. Prior to the tutoring program, Thomas was assessed using the Wechsler Intelligence Scale for Children-Revised (WISC-R). Thomas achieved a Full Scale IQ score of 81 (Verbal Score of 81, Performance Score of 84).

At the time of his participation in the study, Thomas had just completed the second grade. He received special education services for math and spent the rest of the day in the second grade classroom.

### Procedure

Thomas was tutored twice a week over a six week period (13 sessions total). Prior to the baseline phase, the teacher evaluated Thomas and met with his parents and classroom teacher. Based on his educational goals, her assessment, and these discussions, the teacher targeted three instructional areas: deductive reasoning skills, math story problems, and addition and subtraction math facts.

The baseline phase consisted of a series of probes in each instructional area. During each baseline session, Thomas completed: (1) a worksheet with five written story problems, (2) a one minute timing on math facts, and (3) five verbally presented questions involving deductive reasoning skills. Sample items from each of the probes appear in Table 2.

Table 2. Probes for Subject 2.

1. **Math story problem:** Mike builds dog houses for a job. He built 8 dog houses last week. Then he built 17 more dog houses this week. He sold 5 dog houses over the weekend. Mike earns money delivering papers too. He delivers papers 7 days a week. How many dog houses does Mike have built to sell? (20)
2. **Math facts:** Probe sheet consisted of a random selection of addition and subtraction facts (e.g. 7 - 4, 10 - 8, 12 - 9) presented vertically.
3. **Reasoning skills:** All reptiles are cold blooded. A lizard is a reptile. So a lizard (is cold blooded).

### Instruction

After establishing baseline performance, the teacher began instruction in each academic area. Instructional order was varied during each session. The teacher taught Thomas using the relevant strands from *Corrective Reading Comprehension, Level A* (Engelmann, Osborn, Haddox, & Hanner, 1978) and *Corrective Mathematics* (Engelmann & Carmine, 1982). The three strands used to teach Thomas are briefly described below.

**Reasoning skills.** The "Deductions" strand from the *Corrective Reading Comprehension Series* concentrates on teaching reasoning skills central to solving a wide range of problems. As determined by his baseline performance, Thomas needed to begin instruction with the most basic form of deductions: those involving a rule that applies to all members of a class. With this form of deduction, the student learns to apply a "rule" to a specific member of the class.

**Math story problems.** In working with Thomas, the teacher modified the story problem strategy taught in the *Corrective Mathematics Program* as follows:

When working a story problem, you:

1. First read the question at the end.
2. Underline what you're being asked to find out.
3. Go to the beginning of the problem and read it
4. As you read, underline words that are the same as the words in the question.
5. Figure out if you should add up or take away.
6. Do it.
7. Write out the answer.

Thomas was taught to solve both addition and subtraction story problems that contained a variety of distracting information.

## DI with Brain Injured Students—Continued

**Math facts.** Over the course of the tutoring program, Thomas practiced five addition fact families (the 5+ series through the 9+ series) and two subtraction fact families (the 9- series and the 5- series).

### Data collection

The teacher collected probe data twice during each session (before and after the lesson). Each day, she collected and scored Thomas' worksheets after he had completed them. A research assistant independently scored 24 of Thomas' worksheets (8 from each instructional area). Interobserver agreement on these measures averaged 99% (166 agreements out of 168 responses).

### Experimental design

A multiple baseline across content area was used to evaluate the effectiveness of the tutoring program.

Instruction was introduced sequentially in each area once baseline performance stabilized.

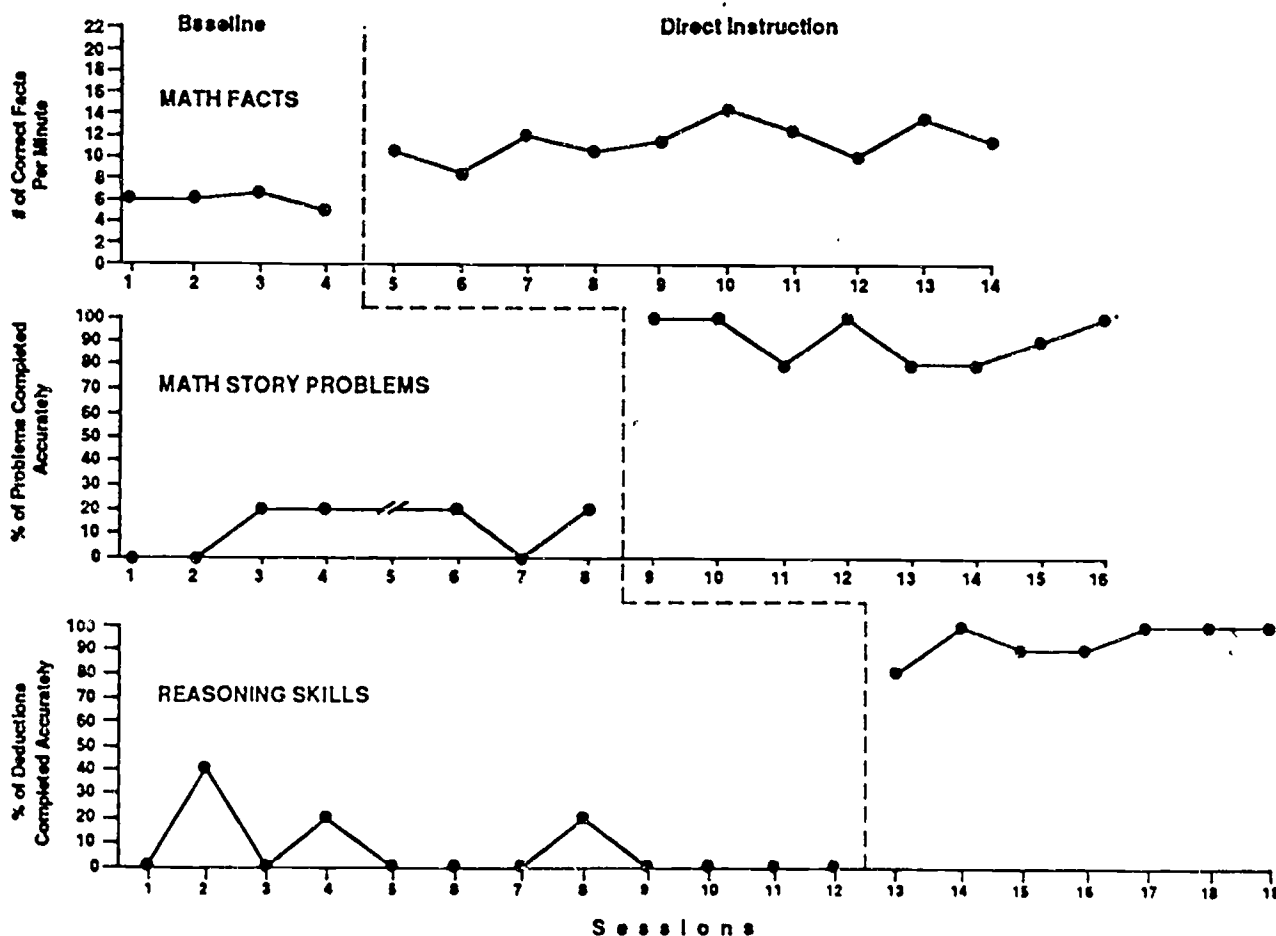
### Results

Figure 2 depicts Thomas' performance in each of the three instructional areas. Once instruction was begun, Thomas made immediate and significant improvement in all three areas.

**Reasoning skills.** During the baseline phase, Thomas averaged 6.7% correct on verbally presented deductions. His responses indicated a complete lack of understanding of the reasoning process, and often included totally irrelevant information. A sample of Thomas' responses (in italics) to the deductive statements presented during baseline follows:

*Some ice cream has nuts. Chocolate is one ice cream. So... lick 'em.*

Figure 2. Effectiveness of Direct Instruction Tutoring in Math Facts, Math Story Problems, and Reasoning Skills (Thomas).





All mice have tails. A field mouse is a type of mouse. So a field mouse... *has little shark teeth.*

Some mountains have tall peaks. Mt. Jefferson is a mountain. So Mt. Jefferson... *doesn't move.*

During the baseline phase, Thomas' responses demonstrated a complete misunderstanding of deductive logic. As soon as instruction began, his performance improved dramatically. He no longer guessed or offered irrelevant responses. For example, several days after instruction began, he responded:

Mammals are warm-blooded. Kangaroos are mammals. So kangaroos... *are warm-blooded.*

Cows don't eat meat. A Guernsey is a cow. So a Guernsey... *doesn't eat meat.*

Thomas' performance maintained at the 80-100% level throughout the instructional period, an acceptable instructional range for a student with learning problems (Anderson, Evertson, & Brophy, 1979).

**Story problems.** Thomas' performance in story problems followed a similar pattern. As soon as the teacher began instruction in the story problem strategy, his accuracy increased significantly, from an average of 11.4% correct in baseline to an average of 91.25% correct during instruction.

Because all steps in the problem-solving strategy are critical to its successful implementation, it was important for Thomas to learn to follow all steps in the problem-solving strategy. Initially, the teacher guided him through each of the steps, providing corrective feedback as necessary. A key component of the instructional process was to fade these teacher prompts.

**Math facts.** During the baseline phase, Thomas completed an average of 6 facts per minute. His rate increased to an average of 11.5 facts per minute during the instructional period. Although this represents a significant increase over baseline performance, it is still considerably lower than what an average third grade student could be expected to complete. Thomas' slow performance can primarily be attributed to his poor fine motor skills. If he had given the answers orally rather than in writing, his performance would likely have increased substantially.

### Discussion

The results of these two case studies show that the Direct Instruction approach can be effective in teaching children with brain injuries. After approximately 12 hourly instructional sessions, both students made substantial academic progress in their targeted instructional areas. The gains were seen in both discrete and more complex skills. For example, Jill improved in reading sounds and repeating simple sentences, and Thomas learned to work math story problems, a skill involving more abstract reasoning. Obviously, continued Direct Instruction for these children would be

important for their future functioning. However, it is a tribute to the power of DI methodology that significant effects can be demonstrated in a short time.

Through participation in the tutoring program, both students regained skills lost after their injury. In addition, some of the gains made represented new learning; Jill, for example, had not had reading instruction prior to the study.

It may be argued that the effects demonstrated in these case studies can be attributed to factors other than the instructional methodology implemented. Students may have improved over the course of the tutoring program due to practice effects or the individualized attention provided by the tutor. Although the design of these studies does not permit an analysis of these questions, research with other populations suggests that the design and presentation variables of Direct Instruction programs are functionally related to student academic gains (e.g., Carnine, 1976; Carnine, 1978; Gersten & Carnine, 1986). Further research is needed to more fully document the effectiveness of these instructional design and presentation variables with the brain injured population. Of specific interest is a more fine-grained analysis of the relative effectiveness of the Direct Instruction design and presentation variables (e.g., cumulative and integrated review, rapid pacing, general-case programming, skills sequencing).

Results from these case studies suggest that the use of Direct Instruction teaching techniques resulted in substantial student progress over a six week period. As the population of children with TBI increases each year, so does the demand for effective approaches to meeting their instructional needs. There is a great need for continued investigation of the effectiveness of Direct Instruction techniques in meeting the the complex instructional needs of students with TBI. ♦

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Conference Announcement...

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**"You Can't Imagine Unless You've Been There Yourself":**

**A Report on the Concerns of Parents  
of Children with Acquired Brain Injury**

You Can't Imagine

"You Can't Imagine Unless You've Been There Yourself"  
A Report on the Concerns of Parents of Children with  
Acquired brain injury

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A relatively new and growing population of children and youth has entered the public school and community service systems for persons with severe handicaps: children and youth with acquired brain injury (ABI). The discovery and dissemination of new medical practices has reduced mortality rates for people who experience severe head trauma (Sachs, 1991) The use of improved emergency procedures such as emergency medications which prevent brain swelling immediately following accidents, as well as the increased availability of pediatric intensive care facilities have contributed to these outcomes. Children and youth with the most severe trauma experience a period of time when they are comatose and require intensive medical care. After emerging from coma these individuals require intensive rehabilitation efforts to try to reestablish as many skills and functions as possible. Severe acquired brain injury results in permanent disabilities. Because of the plasticity of the brain and the normal malleability of children's development, long term outcomes are not easy to predict. Children can continue to regain skills during at least the first year following coma. Subsequently, they can benefit from instructional and rehabilitation efforts. Nonetheless, for children who sustain the most severe injuries, life long supports are required to enable participation in school and community life. These children frequently experience serious cognitive challenges and often face other sensory and neuromotor challenges.

When a child or adolescent experiences a severe acquired brain injury, the family also experiences trauma and may also need, at least intermittently, special supports to promote normal family life ( Florian, Katz, & Lahav, 1989). The life course of a family whose child experiences

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ABI is somewhat different than that of a family of a child who is identified at birth or shortly thereafter as having a congenital disability. In the former case, the child experiences a sudden trauma that changes him or her from a normal child to a child with severe disabilities. The purpose of this report is to describe parental experience of a child's sudden traumatic brain injury so that professionals who work with these parents might have a better understanding of the difficult experiences parents have survived. It summarizes the stories of several parents who described their experiences during the first year following their child's injury. Because of space limitations, this report does not describe children's return to school or reintegration in community and family. The study used qualitative research methods in order to develop an insider's view of the experience ( Bogden and Biklen, 1982) and also to try to make real to the reader the particular lived experiences of parents ( Guba and Lincoln, 1989).

### Method

#### Subjects

Twenty five parents of individuals with severe acquired brain injury (ABI) participated in this study. Subjects were recruited by local chapters of the National Head Injury Foundation and by staff of a rehabilitation hospital. Ten parents participated in a day long focus group in which they were asked to recount their experiences surrounding their children's accidents or injuries. Ten parents participated in lengthy structured interviews in which they were asked to recall their child's injury and their means of coping with resultant difficulties. Questions emphasized the topics of stress, coping and social support. The focus group proceedings and the interviews were transcribed for analysis. An

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additional group of six parents participated in a stress management class in which parents were encouraged to recall their experiences surrounding their children's injuries. The first author collected field notes during this eight week group that met for a total of 16 hours. Ten of the subjects came from urban areas in the Northeastern United States and sixteen from the Pacific Northwest. Subjects included mothers and fathers, married and divorced parents. The time since their child's injury ranged from one year to ten years. All of the children and young adults with ABI required intensive educational support services. All had severe cognitive sequelae from their accidents. Children ranged in age from 3 years old to 40 years old at the time of data collection. All of the parents were English speaking, of Euroamerican descent. The majority of parents were middle class; two were upper middle class professionals, and two were poor and relied upon public assistance

### Data Collection and Coding

Data was collected in group and individual settings. The authors asked a few general open ended questions ( e.g. "Please tell us the story of what happened to your child and how it effected you.") followed by more specific probes ( e.g. Who took care of your other children while you were in the hospital?). Parents were asked to describe what happened to their child and how they responded. In order to encourage parents to provide as much detail as possible in their answers, closed ended questions were asked to elicit detail about their thoughts and feelings in response to the situations that they described and the ways that they coped with extremely stressful circumstances. We asked parents to tell us about other people who were helpful to them in coping with a child's traumatic brain injury.

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Transcriptions and field notes were coded for themes that emerged from a careful reading of the material as recommended by Glasser and Strauss (1967). Initially a large number of discrete code categories were developed. Subsequently, these were reduced by using superordinate themes that subsumed smaller discrete categories. Code categories were discussed by the authors in order to obtain agreement on how to label different portions of the transcript. We identified critical incidents and key excerpts that exemplify the major themes. In the presentation of results, we center each major concept around a quote from the transcripts. The summary that follows emphasizes those aspects of the experience of ABI in the family that were mentioned by a majority of parents.

### Results

When parents of children with acquired brain injury talk about their experience, they organize it as life history that they divide into phases.

...the time of the accident, the occurrence, and what we had to face dealing with the immediacy of it and then the stresses that we faced returning home, in the community and currently.

The order to parental accounts derives from the major events and stages that unfold in the history of a severe head trauma: the accident, the period of coma, the period of intensive rehabilitation, the period of reintegration into the home and school. In presenting the themes that parents expressed in interviews and nominal conferences, we will preserve this order.

The time of the accident... what we had to face with the immediacy of it.

Parents remember the events surrounding their child's trauma in the vivid detail that characterizes our most powerful life experiences. They



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remember where and when they learned of the accident and communicate a sense that they were instantly plunged into a new and dire dimension of life.

My son Patrick called and just from the tone of his voice I knew something dreadful had happened. I knew the minute I heard his voice it was just like a zombie talking. No change of inflection, 'Mother there's been an accident. Peter's been hurt.'

... I came on to the accident scene and immediately recognized my boy's bike in a crumpled state and that was, you know then went into auto drive. Everything went on automatic at that point.

Involvement with the emergency medical system began very soon after the accident for most parents. Depending on where they lived, most had to deal with emergency transportation. Distressing encounters with the medical system began immediately. Parents felt shunted aside.

A lot of damage is done to parents before their children are in the hospital. These EMT's, the ambulance crews, the fire rescue people, need to understand that not only is the person lying on the ground or in the water injured, but so are those parents, and they need to be taken into consideration immediately.

Themes emerged in the different accounts of these confrontations: separation and isolation from the injured child, a lack of recognition of the parent's need for comfort and information, the need to make vital decisions under great pressure, a need for extraordinary efforts and endurance, and a fight against hopelessness.

We had been told nothing. All I knew was my son was bleeding from the head skull. Scalp injuries bleed tremendously anyway. I had no concept of what we were looking at. I stayed with him. I spent 57

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hours in care with this kid. He was released to me 24 hours post-op and I was supposed to handle this? I was scared to death.

Several parents heard very negative prognoses at this point.

That first night it happened I that, that really was stressful. They called me up here at like one o'clock in the morning and asked me if ah, I was his dad and I said yeah. And they said well, there was an accident and I said well how bad was it? They said 'he's not dead yet'.

Another mother was told of the severity of her son's accident at work:

They said he was not a candidate for survival.

There was a strong sense of events being out of control.

You start to learn about the fact that you can't control a lot of things but, like when you've had a good life, and you've had a good marriage and you've lived in this garden and watched life grow beautifully why you tend to forget these tidal waves that can overwhelm human beings.

Under these conditions of extraordinary stress, parents often were required to make major decisions quickly and with little information or assistance. In retrospect they wished they had some help with these decisions:

...from the very beginning, to have someone who is very knowledgeable about head injury to help you because there are a lot of decisions that have to be made right from day one.

When children were initially received by small hospitals they needed to be transferred to larger care centers. Parents were sometimes asked to choose the hospital but were given little or no information about

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alternatives. One parent reported being asked to select a neurologist without any prior information about the choices.

The time surrounding the initial accident also had a strong impact on the rest of the family. Several parents reported that extended family members helped out during the first days after the accident. Family members provided practical help such as watching siblings who were left at home and taking care of the house. Others stayed in the hospital to keep the parent company. During the emergency room and ICU period, some parents noted that friends provided relief during this crisis time.

The crisis also swirled around the siblings of the injured child. Often brothers and sisters needed to be cared for by relatives and had little idea of what was happening. In looking back some parents were concerned that the accident and subsequent separation from parents was also a trauma for siblings:

...his emotions have been on a roller coaster near all the time now so I don't know if that's related to the accident or not. I think it had to have been traumatic for him cause, you know, at the scene of the accident, I mean, he was literally handed to a friend and didn't see either my wife or I for over a week. You know, not knowing where, where his mom and dad were at when he was four years old...

The disruptions in family life were often extensive. Normal schedules and routines were set aside, sleeping and eating patterns altered, and usual patterns of communication distorted by the enormity of parent's emotional reactions.

Parents had very mixed reports about the quality of the emergency medical care that their children received. Reports ranged from that of one parent who had high praise for the staff of a small rural hospital that

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treated his daughter to reports of alleged negligence and malpractice. Some parents had shocking stories to tell: a child left unchanged and uncleaned in a full body cast for four days, another whose wound was stitched in the emergency room without cleaning it, another parent believed an ambulance crew was responsible for his child's experiencing heart failure and subsequent brain damage on the way to the hospital. Thus for many parents the encounter with trauma care was the beginning of a very mixed and often conflicted relationship with the medical and related health professions that treat persons with ABI.. The next stage in this painful odyssey was the period of the child's coma.

### Coma

All of the injured children and youth described in this study experienced coma following their injury. The comatose state lasted for periods ranging from a few days to several months. Several themes regarding the period around the coma emerged from the interviews: great uncertainty and lack of information, a struggle to maintain the personhood of the child, a struggle to maintain hope, the value of personal caregiving, and the emotional drama of recovery of consciousness.

During the time that the children were in deep coma, parents struggled with preserving both the personhood of their loved one as well as hope for survival and recovery. When their children did not respond in anyway to the environment, parents had little to go on other than hope. Physicians often either communicated negative prognoses or admitted that outcomes were completely unpredictable.

Peter had three major systems breakdowns and you see he had to be fed through tubes. I mean when you're in a coma a month why, I

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mean your body is really thrown into low and eight days after the accident, why they wanted me to take him off of life support ...

They just didn't know...he was in a coma for like six weeks and in intensive care for six weeks. And, we never knew and the doctors couldn't give us any hope. They just didn't know. They'd keep telling us well, we got to wait till the swelling goes out of his brain before we know what to expect.

For some parents negative prognoses at this phase were causes for both anger and pride and determination later on. The anger was directed at the doctors for not having hope. The pride was for their children's unexpected recovery, and determination to continue trying to obtain improvements even in the phase of negative predictions.

I have survived, and I'm pushing for more, because every doctor I have spoken with told me, 'Your son will never come out of a coma, and if he does he will be a vegetable.' Vegetable now is growing flowers and doing well.

One mother described her wish that the neurosurgeon would have been more direct in communicating some hope.

We knew it was serious. We didn't need a doctor to say that. What we needed to hear is there's always hope but it's very serious. I mean, and it's, you know, what is it? Six or seven words. And I don't think they have to be able to do any more than that. Perhaps shake your hand or hold it, look you straight in the eye and say 'This is very serious. But there's always hope.' But you see, that wasn't given to us at all.

I just had to have someone seeing my son as a real special human being.

The children lay in hospital beds and often were hooked up to tubes and equipment. They were changed, sponged off, and tested by nurses and

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physicians but did not interact or respond to any of these caregiving efforts. In this circumstance, it was important to parents to maintain relationship with their children as persons; that is, as people with thoughts and feelings, a personal history, preferences and wishes even though there was no visible evidence of any of these personal conditions still existing. At the same time, parents still felt shocked and frightened.

He was really out of it you know, tubes at his head and a sack gathering up brain fluid, so you know, and, and he looked so bad he just looked so bad. That that was really frightening. Scared me.

Parents tried hard to maintain a relationship with their comatose children by talking to them and touching them as if they were responsive. Efforts to communicate were both aimed at trying to elicit recovery as well as to maintain person to person close emotional contact.

We would go in and work with him.. We'd take a key and rub on the bottom of his foot when he was in intensive care to see if there was any reaction whatsoever. And it was quite a thrill the day that ah, we saw him move his toes.

I couldn't bear the thought of my son laying in intensive care with people that didn't know him, didn't care about him except as a body that they were responsible for. They didn't notice this gift. And so I collected photographs from different places. From the time he was in preschool, well from the time he was a baby. And I put that in his room in the intensive care unit. And I wanted so for him to become a person to somebody. I knew that it wouldn't effect certain people but then for others that key to a visual image... It was because I just had to have someone seeing my son as a real special human being.

Some parents felt that in the effort to save their child's life the medical staff lost sight of their child's individuality and also of the parent's emotional pain. With some exceptions in which parents believed



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they received substandard medical care, they felt that the hospital did a better job of taking care of the patient's physical needs than of the child's and parent's psychological needs.

Well, of course, I want you to fight for his life. You know, I don't want one centimeter of effort lost in his behalf. But I think that professionally they certainly did their job. Psychologically, no. I mean it was incredible.

Many parents were critical of the lack of concern they encountered from some professionals. Complaints about professional communications centered on two areas: lack of knowledge about head injury and lack of concern about what parents and family members were experiencing.

Do you know that in the early stages when it was getting towards the point where our daughter was returning home, that the insurance company had us visit a psychiatrist. It was a total waste. I could have told that girl things. She didn't know beans.

I saw the neurosurgeon. I didn't see the man for a week (after his daughter's surgery) and he says, 'I suppose you would like to talk to me.' Prior to that he said, 'If I have anything else to tell you I will tell you.'

When asked about who was supportive of them during this period, several parents mentioned nurses who were helpful. Some parents mentioned having favorite nurses. Others said that the nurses gave them much more information than the doctors. One parent described how a nurse taught him how to care for his son by washing him and that being able to help with this kind of personal care was very important. One parent complained that the hospital rotated a favorite nurse to different duties and thus terminated an important relationship.

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The coma and intensive care phase often lasted for weeks. Parents had to cope with finding care for children at home, dealing with jobs and the other normal demands of life that had to be set aside for this crisis. Parents whose children were moved to centers far from home had to find places to stay near the hospital or commute for long distances. During this period of protracted intensive care some parents began to experience the first tastes of social isolation which later became a major concern.

It's like you're an island. You're isolated. People don't want to step in to these situations. I mean, I think that the level of pain is so great and everybody has so much pain already, so many troubles of their own to deal with that you tend to be shunned from the very beginning.

Other parents continued to have the help of friends or relatives during this time and they remembered it with appreciation.

The emergence from deep coma and gradual return of skills marked a new time for parents. Most had little idea what to expect. One parent said that all he knew about coma was from watching television and he thought that when a person emerged from unconsciousness, that she would wake up and have her full faculties. He also assumed that progress would be steady and without setbacks. When the course of recovery was very gradual with many ups and downs, this parent was bewildered. Each step forward represented hope of the child returning to normal and each step back raised the fear of the child regressing back into coma or failing to recover. Once again parents were not given information about stages of recovery from coma.

Every parent had a vivid memory of moments when they first were able to reestablish communication with their comatose child. In

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retrospect these occasions were very important to them and were remembered with feelings of joy and gratitude.

... a thrill when we'd say, 'Darell, this is Dad. Do you hear me? If you do, squeeze my hand.' And he'd squeeze, you'd feel his little squeeze in the hand.

Initially it was really tough because we was unresponsive. And then when he responded uh, it was the fourth or fifth day, it really lifted our hearts. And then to be with him and watch him progress from originally not being able to communicate at all to at least being able to say something at the end of the four weeks. . . really did us some good.

...by the time he was able to talk to me there was I don't think any shadow of death left. But this would have been sometime during the... fourth or fifth week...that was a joyous, joyous, joyous time. And you know, Lord the smile. Oh, my. He was so glad to see me and I was so glad to see him. We just sat there and smiled like fools.

This experience of the reemergence of a loved one after going away into coma and hovering near death was a very powerful one. It often appeared to the parents to defy the negative predictions of the doctors and to similarly challenge the seemingly impersonal nature of hospital care. Thus in the parent's experience there was very strong emotional evidence that they had good reason to hope for their child to return to normal. This hope was reinforced by the gradual reacquisition of skills during the first year following the accident. For some parents it did not become clear to them that their child was forever changed for a long time after the accident. And they had strong experiential evidence to encourage them to believe that eventually any sequelae would lessen or disappear altogether. Again, in retrospect, parents wished that they had been given much more

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information about the long term impact of severe head injury. In particular, they wished that they had been informed about the changes in social behavior and personality that are usually associated with severe ABI.

### Rehabilitation phase.

Most of the children studied required several months of intensive rehabilitation before they were able to re-enter their homes and school systems and return to a semblance of a normal daily schedule.

After recovery from coma children were either transferred to rehabilitation hospitals, or in areas with no services, were sent home. In the rehab units, parents learned that the professionals had a different focus in working their child. The emphasis shifted from biological survival to the recovery of previous mental and physical status. And in this phase the child had to be much more of an active participant and ally. When it was time for children to enter rehabilitation, some parents first encountered the scarcity of services for pediatric rehabilitation. Some parents had to bring their children home and manage the rehabilitation the best they could. Others believed in retrospect that the rehabilitation program that their child received was not really designed for children but, instead, that staff had primarily had experience with adult head injury victims whose needs were different. Other parents had to send their children far away from their home community for rehabilitation. One sold her home and moved to the city where services were available.

Once again parents recall the rehabilitation phase as all absorbing. Normal family routines and schedules as well as social interactions were disrupted as parents either spent a lot of time in the hospital or devoted a

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great deal of time to the child's rehabilitation at home. Several parents described the need to commit large amounts of their time and energy to helping their child to recover. For many these efforts were exhausting. For the most seriously injured children, the demands of caregiving continued from the rehabilitation phase up to the present. Exhaustion began to take a toll during the year following the injury. Caregiving demands in addition to being tiring were also isolating.

My wife gets up at 5:00. She has a difficult time a lot of days to find time to go to the bathroom or eat. Many nights my wife doesn't eat because she is doing the laundry... and she sleeps in the same room with my (brain-injured) daughter. There is nothing like going to any social meetings. We don't have time for that kind of stuff. Geez, I don't know where anybody finds time to do that.

Parents wanted to believe that absolutely everything possible that could be done for their child's recovery, was done. It appeared that it would be unacceptable to parents to believe that less than 100% of the possible was attempted. Given the limitations available in rehabilitation services and their tremendous costs, this meant that a major amount of rehabilitation and caregiving work fell to the parents and that they held themselves to very high standards of what they must provide.

...I always said, well, my biggest problem always during this year of intense effort, it's sweat. Oh, God he works so hard. By lifting weights you know, with his hand and on his ankles and sitting on a big ball trying to keep his balance and I went out and bought him the sturdiest bicycle I could find because I didn't want those leg muscles to atrophy while he couldn't walk.

This parent's son cooperated in the rehabilitation efforts. Anything he was given to do, he worked hard to accomplish. Except that he refused to

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go outside of the house. He was still unable to communicate fully and his mother was unable to understand his resistance.

And I finally reached that point where he could give me enough of an answer. He didn't want to go outdoors until he was all well. And I realized that there had to be a great push made to break that...(his decision that)...if he was going to be outdoors he had to be 100% well. And so I got him a puppy for Christmas and he had to walk his dog. That was the only negative I saw in Peter...was that he didn't want to go outside until he was all well.

Often these efforts entailed a high personal cost; they had an impact on relationships within the family, social ties outside of the family, and the fiscal status of the family. Some parents reported that they did begin to learn to balance their own needs with their child's.

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



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But others found their child's needs so compelling that, in retrospect, they felt that relationships with spouses and other children suffered.

I think the first thing that came to mind on my list (when asked about stressors) was the family relationships and how do Brendon (spouse) and I cope with the stress that occurs between us because of the injury.

It's just that we are always so busy. There is no time for a relationship between us, and we are the foundation for our family.

In some couples, the accident and subsequent caregiving strained the marriage to the breaking point.

My husband insisted on her (daughter with head injury) going home because there was no place except for a place in Jersey where they wanted to just put her away and forget about her, and my husband insisted on her coming back...after about three months, my husband left, he couldn't cope with it anymore...

My son was hit by a car eight years ago. He has spent about four months in ICU (intensive care unit for coma) and then he went to Sunnyview (rehabilitation hospital) for another four months. I just think that this accident ruined our lives completely because my husband couldn't cope with it. I didn't have any help...we went to all the counseling, and it still didn't save the family.

We are here (at the focus group) because we survived. I know a person in (our) situation who cannot cope at all, who can't do it, and how many husbands or wives have walked out and have washed their hands?

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Coping with the accident and its aftermath did not break up every marriage. On the contrary, some parents reported that it brought them closer together. Another couple described the accident as both bringing them together and also causing more occasions for arguments.

I think that initially it brought my wife and I closer together but then it probably pulled us apart. It gives us more instances to disagree... how we should proceed with Dennis and do things over dealing with our other children...I think that had we not been where we were, it might have torn us apart...We knew we had to hold together, that to survive with the family.

### Coping with personality changes and behavior problems

One of the most divisive issues in some families centered around the injured child's problem behaviors after the accident. Closed head injury often involves trauma parts of the brain that are critical elements in the generation of behavior that we normally think of making up personality. ABI victims commonly experience difficulties with social judgement, normal affective behavior, and impulse control. After the child has returned home and his rehabilitation process has been underway, these social and behavioral challenges emerge for many parents as the one of the most difficult legacies of the trauma. Some of the personality changes were relatively benign:

Dennis was somewhat quiet and introverted before the accident and he's very outgoing and extroverted now...he's not afraid to go walk up and give someone a big hug. You know, for an eleven year old boy to do that now, you know, that's not cool. Dennis doesn't even think about it. He goes, if he wants to give somebody a hug, he does it.

It isn't that the symptoms are different. It's that the controls aren't there. For instance, I can remember with Brendon; he always had a hot temper but before the accident he was cool. After the accident it hit the fan. All those controls were gone. His main problem was

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ah, he was still 17 years old and he thought he was very popular with the girls and he'd try to make out with the girls and he'd try to make out with every girl he saw.

(Before the accident) He just didn't talk much and he was always very close to his mother when he was growing up and , then after he started talking, come out of the coma and started to talk, he never shut up. He just talk, talk, talk. And a stranger, he didn't know what a stranger was. And he just about talked us to death (laughter).

The problem of disinhibition, a loss of normal constraints on emotional reactions, was much more serious for some parents. It was particularly difficult when the impulsive behavior involved anger and aggression.

I went to him ( 14 year old boy with ABI) and said, 'Son, what have I done to make you so angry? I have tried so hard to stand beside you, in front of you, with you. Why do you hate me now? What have I done? Can I fix it?

Parents reported that the onset of behavior problems took them by surprise. Again they wished in retrospect that they had been given more information about the probability of behavior problems and personality change associated with ABI.

Is it possible that this head trauma, this behavior, is a direct result of this trauma? Is there a guideline to what head trauma kids go through? You have a progress with almost any disease.

When these problems first emerged, parents and professionals did not attribute them to brain injury and, in some cases, the children were given inappropriate kinds of treatment.

Like I said, we anticipated physiological problems. We did not anticipate what appeared to be psychiatric problems. ...my husband

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and I went through a crisis of our own questioning alcohol and drugs (whether or not the injured adolescent had a drug problem)...and we ended up forcing him to voluntarily commit himself. Had we realized, had we known...we could have taken the appropriate measures then, taken him to who he needed to see instead of putting him through 60 days in a private psychiatric hospital where he was subjected to (people who experienced) alcohol abuse, drug abuse, suicides, homicides, personal mutilation, all of the things that I --- when they were born, I never wanted them to see.

It is important to note that not every child experienced serious behavior problems and that, in some cases, the kinds of personality changes that occurred were viewed as positive. For example, two parents talked with admiration at the way their children continued to work to recover from the injury and to face challenges posed by their altered abilities.

I live on a day-to-day basis. I feel she is doing super. She is a very positive, patient kid. No fear. And one thing we can't compare today what Kelly is like to her first fourteen years except she has not lost her determination and we go day-by-day and each day we learn to accept what we have to accept, but I'm not done and she is not either.

In our interviews with parents of young adults with head injury, we found that some parents were still very concerned about social and behavioral problems several years after the injury. One father described his irritation at his son's temper and argumentativeness. Another described continuing embarrassment at the way his son, now an adult, would approach strangers and strike up conversations that were inappropriate.

In some cases behavior problems were cause for dissension within the family. In cases of anger and aggression, the child's problem behavior raised interpersonal tension among other family members.

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It almost got to the point of domestic violence. We were so frustrated, and he was violent, and we had no support.

In other instances, family members became divided over their view of the problem behaviors. In one such family, the mother attributed her son's difficult behavior to his injured brain and assumed that it was out of his control. As a result, she viewed him as essentially blameless. On the other hand, her husband had the view that moral behavior was always under a person's control regardless of brain injury.

And I told him, I says Sean, you know, you know in your mind what's right and what's wrong. And some of the stuff you pull is wrong. And you know it's wrong. Don't do it. But he just, he just won't listen.

Siblings in this family were also divided in their opinions; one sympathizing with the brain injured brother, the other blaming him for acting in problematic ways.

...his brother George, he's the oldest...gets along real good, cause George was always the bad boy in the family...Now my second boy, he won't have nothing to do with Sean. He bugs, Sean bugs the hell out of him and he won't have nothing to do (with him).

Changes in the child's personality pose one of the larger challenges for parents in their longterm process of adapting to the effects of acquired brain injury on their child, themselves, and their family. Parents described how this process involved both coping with the loss of the child as he used to be before the accident and accepting a new, changed person.

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Parental experience in coping with a brain injured child involves a simultaneous process of grief and adjustment. For many parents, even years after the accident, there were times of strongly felt sorrow as if a child had died. At the same time, they needed to relate to the changed child. The mixture of emotions was somewhat confusing and, as with many aspects of their experience, parents felt that other people could not easily understand this mixture of thoughts and feelings.

I mean it was like schizophrenia. I'm looking at this kid who looks the same. A little bit of balance problem, a little deficiencies, but this is not the same kid. I'm going crazy. My husband is going 'You're fine.' My mother-in-law is going 'You're psychotic.' I needed to have someone who I felt was solid, someone trusting, a professional someone who has the education to tell me, 'Yes, Ruth, it is fine. Tear your house apart. Scream and yell and mourn this child.'

This process of mourning for loss of abilities and accepting a changed person also happened for many of the injured children. That is, they remembered themselves prior to the injury and have to come to terms with their own loss.

The crucial thing is that the child himself knows he is different. If you can't accept the new kid, the new kid can't accept himself. He is fighting you every day.

Some parents expressed bewilderment about what to say to their child about the loss of abilities.

For some parents the accident and loss of their child-as-known-before occasions a loss of meaning. One father spoke bitterly about his loss of faith in God.



## You Can't Imagine

Do you believe in God all of you? Did you ask and you receive? Did you ask to receive a brain-injured child?

Another mother described, almost poetically, the way in which the accident not only raised grief about loss of the son she had and hoped for but also how it brought to the forefront other feelings of being cast-out by the benevolent side of life.

I no longer believe that if you work at life it lets you walk off into a beautiful sunset. So where does that leave me? Still trying but not really believing? Off the track permanently? Yes, there is a God and his purpose but my faith is an imperfect vehicle... My former identities as a wife and mother, I'm sorry, have eroded and disappeared in a cloud of dust leaving nothing in me that is coherent.

Some of the parents also described a period of time in which they experienced guilt and anger. One parent mentioned the fact that she had bought the bicycle that her son was riding when he had his accident as if she might have prevented it if she had not purchased the bike. Others expressed the worry that they were not doing enough for their child's rehabilitation.

The guilt encompasses many, many things such as, "Am I doing enough? Could I have prevented this ABI?"

Parents expressed the wish that the professionals who worked with them would know how to counsel them about guilt and grief--or, be aware of their feelings. They felt that social workers, therapists, and counselors needed to be educated about the effect of head injury on parents.

## You Can't Imagine

We need to get to our mental health people. ...(they) need to know that the minute they find out there is a head trauma injury involved undoubtedly the parent is going to feel guilty, that they are going to feel the definite mourning process because the moment that accident happens that child and their lives are changed permanently forever, completely...

Dealing with such strong emotions and pervasive feelings of doubt was a solitary struggle for most parents. Again and again they mentioned their difficulties in making themselves understood by others.

Social isolation, the communication of stigma and the creation of a handicapped identity.

An injured child's status is often unclear for a considerable length of time following a traumatic brain injury. Realization that the child is permanently changed as has a different identity as viewed by the world is communicated by some key events that happened after the child returns home and is returned to public school. During the period of time when parents were beginning to understand that their child was permanently changed, they were simultaneously receiving powerful messages from their social community.

The biggest disappointment was later on when the friends and his friends... just kind of faded away from us.

Several parents discussed their perception that the accident and subsequent changes in the family's life resulted in social isolation for both parents and the injured child. Most parents indicated that family and friends were available during the immediate crisis following the accident and that their practical support was of critical importance.

## You Can't Imagine

...my husband's brother's wife had enough objectivity to deal with this...She was instrumental in getting someone to clean my house, someone to mow the lawn, someone to take care of our other kids.

Others described relatives or friends who visited the hospital while the child was in the ICU. One parent told of a good friend who would sit by the child's bedside at night so that she could get some sleep. The injured child's school friends were also active during this crisis time. However, after this initial period, supportive people began to withdraw. This process of withdrawal from the family and child communicated to parents that their child had a new identity, one that was devalued by the larger community.

...at the time he was in the hospital...we had several friends that came up to see us and to see Darell. I guess the biggest disappointment was later on when our friends and his friends found out that it was more of a permanent situation, then they just kind of faded away from us and, especially his friends. They just stopped coming around. Didn't see him any more and that was kind of heartbreaking.

The loss of school friends can be partly accounted for by the amount of time that the children miss in school. They often miss a full year of schooling so that their age mates have moved on to a new grade level upon their return. Also, the same kinds of physical and psychological changes that require parental acceptance intrude on friendships. For example, the father of an eleven year old whose son had become uninhibited about showing affection to peers since his brain injury described the effect these behaviors had on peer relations:

## You Can't Imagine

You know, that isn't cool now for him to be doing that. He gets the peer pressure for that...

Other children were subjected to teasing because of their altered abilities.

...it's so awful to have people look at your child like he's stoned or drunk because he doesn't have good ...balance. I wouldn't care if he didn't have both of his legs. He's still the same person but it's awful the judgements that we lay on other people. You know, they have these crushing expectations.

People make these assumptions. If you don't talk absolutely clearly why you're mentally retarded or else there's something wrong with you so that these quick assumptions we use to judge people by are continually working against anybody who is severely handicapped with head injury. And just because you may be slow in the way you speak or because you can't respond to questions quickly, people write you off.

Many of the children were aware of other's reaction to them. One parent described how she understood that her son was sensitive about other children's reactions to him upon returning to school from the hospital:

I asked him once when he came home. I asked him why he watched the ground so much and he said, 'Well, I don't have to see the expressions on other peoples' faces when they look at me. That was the only inkling that I ever got of how he suffered from awareness.

Thus the loss of the child's friends and subsequent problems of teasing and rejection communicated a sense of social stigma that others assigned to a person with visible differences in abilities. The process of isolation for the parents appeared to be more complicated.

Initially, for some parents, the isolation began as a result of their total absorption in their child's care and recovery. It meant that they had

## You Can't Imagine

little to talk about with other people besides their very strong feelings concerning the hospital, their child's health, and related concerns.

I couldn't (wasn't able to socialize) after that accident. It was like I could live intensely in this loving world with my son. But if somebody came to visit and asked how are things going...I couldn't hardly cope with it...it was like I was somebody that was wound up like a toy and once I got started all this, this anger started coming out...and I was raised, you know, that's inappropriate behavior. You're not supposed to express your feelings like that. And I was appalled with the amount of emotion I was containing.

In the midst of feeling these overwhelming emotions, it was hard for parents to respond to other family members who were also grieving.

... you have your extended family who is there grieving also, and sometimes I think you want to say, 'What are you feeling sorry for yourself about? I'm the one in this situation.' You have to deal with their grief when you aren't even through dealing with your own grief, so sometimes it's even more-- it's harder to have them around depending on the relationship.

The problems in maintaining friendships were also related to the practical demands of caregiving. It was often difficult to get away in order to spend time with family or friends. One parent described the way that their many friends eventually stopped calling to invite him and his wife out because they were always too busy with caregiving after the accident. Finally, one theme that ran through the comments of most parents, was the way they felt that other people simply did not understand them. Partly, this sense of distance from others grew out of the well meaning but nonetheless fatuous comments that people would make. Several parents had examples of unhelpful help:

## You Can't Imagine

...and you get sick and tired of hearing 'I don't know how you people do it. How do you do it?' What (else) are you going to do?

Parents wished for more understanding from the people around them.

If people were more aware of what you have got to go through every day of your life they might be a little bit more understanding. I don't think you would be as isolated if the awareness were a little bit more than what it is...if there was more awareness of everyone around you of exactly what you were going through, the isolation, the social relationships, the burnout, the fight.

Parents wished for this kind of understanding from both friends and relatives as well as from professionals. The process of returning the child to the public schools was also isolating in several cases. The children in this study were intellectually and physically normal prior to their injury. When they returned to the public schools after long periods of time in hospitals and rehabilitation programs, most of them no longer were able to be served in their previous classrooms. All of the children in this study were identified as requiring special education and were placed in programs for children with mental retardation. The process of placement thus entailed assigning children a new label and placing them on a new track in the public schools. For many parents this process of special education labeling and placement represented the first concrete statement from the broader community that their child had a new social status. Some parents felt that their head-injured child did not belong in the same program as mentally retarded children. Others felt that the school staff was unprepared to serve children with acquired brain injury. The complex needs of these children often outran staff skills. For example, one parent reported that her son needed to wear an arm and hand



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splint for an hour a day at school but that the staff kept putting it on incorrectly. Another parent reported that it was necessary for her to train the school staff in how to work with her daughter. She complained that the school's policy of rotating personnel from year to year meant that retraining of new staff would be necessary.

The tremendous variability in school services in different regions and communities was evident in parental reports about return to school. Although, some parents were distressed at the quality of school programming for their children, others were impressed with the range of services that were available:

...(school) has done as much for my daughter as any rehab hospital or anything else. They have licensed therapists, occupational and physical therapists... and the bus comes every morning.

Return to school not only marks a critical milestone in the community's redefinition of an injured child, it also represents a substantial disjunction between two service systems, the medical /rehabilitation system and the public school system. The former system is usually funded at much higher levels by private insurance. Therapies and treatments are delivered in one on one sessions with health personnel and services are viewed as part of medical treatment. Thus reintegration into public school usually follows a period of intensive rehabilitation work either at a hospital or at home. Upon re-entering public schools the children had to share staff time and resources with several others. In some cases, parents were disappointed in the way in which their child's physical and educational needs were not given as much care as previously.

..it turned out for us that we had to be constantly vigilant to make sure that his IEP is being followed.

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Some parents were also disappointed in the way in which the schools were very slow to implement their children's instructional programs. They expected that the IEP would be implemented early in the school year. Once again, it seems likely that expectations are built up during the rehab experience in which children are given one-to-one assistance and programming and that these same standards cannot be readily met in a school setting where there are many more children and fewer resources.

Parents had other concerns about the way that teachers dealt with their children. One parent complained that the school staff was overprotective of his son. For example, they allowed him to nap regularly instead of requiring him to engage in classroom work. Similarly, parents had concerns about how other children treated their injured child and about behavior problems. Thus when children return to the public schools, parents are by no means finished with the job of monitoring and advocating for services nor does their child's adaptation to school necessarily settle into a predictable pattern.

### Concerns about siblings.

Another set of social and emotional issues that parents described focus on the brothers and sisters of the injured child.

My older boy had a lot of problems dealing with his brother, with the illness, with the trauma that he saw.

Acquired brain injury effects every member of the family. Several parents reported that uninjured siblings experienced difficulties as a result of the trauma. Some brothers and sisters developed behavior problems. Others had difficulty in sleeping or trouble at school. Parents

## You Can't Imagine

attributed these problems to the trauma involved in seeing the accident, to the separation from parents during the hospitalization, and to loss of parental attention.

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

Once again, parents desired information about the impact of head injury on other family members and on ways to cope with these effects. One wished he had :

...a checklist to say, 'Is this child in trouble? Do you see this, this and this happening?' Not to the injured child but to the surviving sibling. My daughter couldn't sleep. She had incredible sleeping problems...all kinds of things that we knew that she needed help.

Like their parents, brothers and sisters also struggled with feelings of guilt, loss and grief. One particularly poignant story illustrates these cognitive and emotional reactions that siblings can have and the need for someone to attend to them. One mother was away at the hospital for three and a half months while her daughter was in a coma. She tried to explain coma to the four year old and twelve year old brothers.

We had to explain to both kids that Suzette was sleeping, and she was hurt. She had hit her head and she was hurt. When I first had gone home 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. I opened it because I wanted to--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.'

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Parents were also concerned about the role that siblings should play in caregiving. On the one hand, they wanted the brothers and sisters to be helpful. On the other, they did not want to unduly burden them with responsibilities that would be too burdensome. They also struggled to give enough time and attention to the nonhandicapped siblings and also assist their brain-injured child.

It's a big one (problem)--making sure everybody gets their time, and not putting too much responsibility on the older kids, the more capable kids, in taking care of him (the injured child), though I trust my kids with him more than I trust any other stranger in the world.

### Financial worries

In addition to the social and emotional impacts of caregiving on parents and siblings, the people we interviewed also had many practical concerns about finding and paying for appropriate services for their injured children. The costs of long term care and many inequities in the system of medical payment were a great concern.

With his medical bills alone, it's upwards of \$15,000 that I am in debt.

Medical treatment from the emergency room, to intensive care during the coma, to rehabilitation and follow-up is very expensive. Several parents were faced with enormous debts.

I have a lien on me. I have a loan of \$450,000 from the New York State Department of Social Services for this kid. Where do you get this money?

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Parents discover quickly that money is a key to obtaining services for their children. From the beginning doors either open or close for their injured child depending upon parental resources.

The first thing the rehab play is, they take you in the board of director's room and sit you down at the table and they want to know if you have got insurance before they even take you. That's the first thing they want to know, and if you don't have insurance, they don't want you.

Those parents who had private insurance had complaints about difficulties in getting payments for items such as special equipment. Most insurance policies have time limited rehabilitation payments so that termination of rehabilitation services was often determined by the end of insurance payments rather than by the needs of the child. Other parents were faced with prohibitive increases in the costs of their health insurance once their child became a long-term patient.

Parents who were receiving public assistance had many difficulties in using Medicaid. They found that many doctors would not serve them because the Medicaid payments were too low or too difficult to obtain. Parents who required long term care for their children who did not recover from coma said it was difficult or impossible to find services and to pay for them. Thus these parents suffered from the lack of catastrophic health care insurance and restrictions in public assistance that characterize contemporary health care funding.

Parents had another set of concerns regarding public school services for their children.

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### What helps.

Up until this point, this study has emphasized the suffering and the frustrations that parents and other families members experienced in coping with the acquired brain injury of a child. There was, of course, another side to the picture. Parents did describe a number of formal and informal supports that were of genuine help. They also either described or showed us a variety of coping strategies that have been adaptive for them.

From the outset, parents had to rely on the competence and efficiency of medical personnel and systems for their child's survival. Several parents expressed appreciation for the way that local hospitals served their children. In almost every case, children were close to death after their injury and their lives depended upon the availability of emergency treatment and the skills of doctors, nurses, and technicians. These urgent services were rendered under the utmost time pressures and often in difficult circumstances. Parents were appreciative of them.

They have done a fantastic job under the circumstances. I don't want to see my daughter hurt in the head, but they done a great job in my hospital.

In retrospect, some parents were able to forgive the poor communication skills and lack of interpersonal concern that so often seemed to characterize the people and the procedures in medical settings.

I guess what I am saying is that they have been schooled many times, that they have to protect themselves with this shell, and that shell can hurt you, and you can still be coming off of anger for months and years later from it even though you are saying, 'Hey, it was good because they saved my son.'



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When professionals were able to communicate with both clear information and empathy, parents were very appreciative. It was clear that parents desired both professional competence and human warmth--neither by itself would be sufficient.

...the nursing staff was great. They had set up in the pediatric emergency room or intensive care room, told all the shifts so we had the same nurse everyday for Dennis. Actually the same two nurses so we got to know them real well. They were very supportive. Carol (spouse) and they would talk about Dennis' condition and we actually got more information from the nurses than we did from the doctors.

Similarly, when parents had adequate insurance coverage and cooperation from the company, they reported being able to obtain services that made an important difference to their child and their family. One of the parents who had the most fiscal resources available through full insurance coverage was able to hire a personal casemanager to take care of the large volume of paper work that was generated by the many agencies and services that his child required. Another family was able to hire private duty nurses to help with the rehabilitation phase at home. Once again, if the personnel did not exhibit competence, merely having the resource was not sufficient. The combination of adequate resources, professionally competent personnel and good communication was appreciated in the rare instances in which it happened.

Several parents noted that professionals generally were not well informed about acquired brain injury and its aftermath. Many of them found it necessary to read and learn as much as possible about their child's condition; this sometimes put them in the position of being more knowledgeable than the 'experts'. When professional staff were willing to learn from well informed parents, both sides appeared to benefit. In

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addition, continuity of services and personnel was particularly important given the need for special knowledge of their children. A commonly expressed frustration was the frequent turnover of personnel ranging from from the ICU nurses to the special education teachers. When hospitals and schools established procedures that led to continuity of staff, parents were grateful.

Formal services and financial support were only a small part of the resources which appeared to make a real difference to families. Informal sources of care and companionship were at least as important. When it worked well, immediate and extended family were invaluable. When asked if there were any people who were very helpful during the hospitalization, one mother answered:

Oh, yes. I mean, you know, what is greater than a family? Parents reported that family members helped with practical concerns such as house care and child care for siblings as well as emotional support. Similarly, friends and work associates were also important to some parents. One parent described a friend who stayed with her son at night. Another talked about a church group that offered practical assistance as well as emotional solace. Some of the most helpful contact came from other parents of children with brain injuries.

My son swims for a swimming team for the physically limited and one of the boys that is on the team is head injured and, we just met his mother Saturday and my wife talked to her about the common problems we have and seemed to hit something off.

It was essential to parents to make contact with other people who had believable experience with the conditions that they were suffering.

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I need somebody who has been through it or who has been through it with other people --that know what to look for, what problems to look for.

They also wanted contact from the time of the accident with someone who was knowledgeable about acquired brain injury and its treatment. They felt that they were left in the dark for long periods of time and had to make many important decisions in the absence of clear information.

I felt that you definitely need somebody right there as soon as it happens that is knowledgeable and knows the ropes...

One parent was able to obtain both information and emotional support from a staff member of the local Head Injury Foundation and reported satisfaction with this help.

Respite care was also greatly valued. As described earlier, the long-term demands of home caregiving can be exhausting and can greatly limit a family's opportunities for normal activities. When parents and siblings were able to get a break, they usually enjoyed it. It was necessary to find someone who was trustworthy and competent to take care of the injured child while the family got a rest.

We were in a position to have someone we hired to come in and stay at home so that our older boy would have care when we were away. This was invaluable to us.

Another kind of personal assistance that was of great value to some parents was case management. It involved help with obtaining services, negotiating with agencies and systems, and assisting with the 'paperwork'. Parents often had to fight to obtain services for their

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children. When they had an ally who could serve as a mediator and advocate, they felt supported. ...

Parents also reported that community institutions including schools, youth groups, and churches could be helpful. For example, one parent described the way the public school gave emotional aide to her uninjured son at school while she was away caring for her child who was in a coma.

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.

Once again this program could have benefited from more information:

...he really did need the crisis intervention counseling, but the point was 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.

### Parental commitment and coping.

Parents also drew upon personal resources and coping skills. These individuals have been through harrowing experiences that have required them to call upon the full extent of their will and faith. Different parents seemed to emphasis different ways of coping with the many challenges brought on by the injury. These included intensive commitment, persistence, aggressive determination, religious faith, appreciating the progress their children made, and taking a view that some good can come of suffering. For example, here is a statement of the kind of commitment that parents have exhibited to their brain-injured children:

I have given five years of my life for my son.

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Another described his efforts to help his son rejoin the community:

(I) try to make his life as 'normal' as it can be and, I saw him...as being a very active outdoors type boy... so now I find myself helping like in Boy Scouts. I've been a den leader in Cub Scouts for three years...baseball, I've gotten him into baseball, basketball...I've been there to help with the coaches and have given him some help...(to see that) he has individualized help all along.

Our interviews included discussions with parents whose injured children have grown up and entered adult life. Some of these parents were still embroiled in ongoing stresses. However, it is important to note that at least six parents expressed a sense of having come to a resolution of their anguish. In both cases they were reasonably satisfied with the kinds of lifestyle and options available to their children. In one case the adult son was living in a group home sponsored by an organization that his father had helped to start. The father's satisfaction with his son's living arrangements and other services played an important part in his acceptance of the situation. Another mother was interviewed at three years since her child's injury. She talked at length about how the experience had given her a new set of values. She viewed her child primarily as a major contributor to her quality of life and that, in all, she had learned important lessons from the experience.

### Discussion

We have used qualitative methodology that aims to let parents tell their own story and make their own points about their concerns. It attempts to maintain some of the integrity of parent's experience in the process of unifying themes from several different persons. If there is one

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"meta-theme" that emerges from listening to these voices of people in extremis it is that the human tragedy of the permanent damage of a child now takes place in the context of a set of social institutions that are only minimally cognizant of the social and emotional impacts of the trauma on the family. In this "non-system" (it is actually made up of several disparate and non communicating parts), the child is viewed as a decontextualized entity--a body to be kept alive, an arm or leg to restore, a learning repertoire to enlarge. Rarely, is the child viewed as a part of an elaborate social system, a family. Rarely is the family considered to be equally the victim of the accident that leaves these children and their relatives forever changed.

From our interviews with parents of children who were injured years ago, it is evident that parents and siblings are a vital lifelong resource for support for people who suffer from acquired brain injury. Yet from the ambulance attendants to the insurance agents, the many people who are involved in the treatment, rehabilitation, and long term support of the head injured person rarely recognize the needs of family members for information, emotional concern and empathy, empowerment to make choices and be partners in treatment decisions, and concern for the social fabric which surrounds the injured child and the family. The process of humanizing this treatment and caregiving system, of making it "user friendly" will require reform from many angles. On one level new services and resources must be created. Clearly when a parent has a lien of \$450,000 put on him by the state or a child in a coma must remain at home because there is no local long-term care facility, there is a need for new societal resources. But along with additional resources, there is a need for a change in the focus of the medical and educational services that do

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exist. At every stage of the process of treatment and long term care for persons with acquired brain injury there is a need to treat the patient as part of a complex social network and to see parents and family members as of equal importance as foci of concern.

Some important limitations of this research must be acknowledged. First, the size of our sample was relatively small and thus the generalizability of our findings may be limited. Because there are few formal safeguards against observer bias in qualitative research, it is possible that our findings reflect to some extent our own opinions. The findings of this study should be compared to data gathered from other methodologies in order to examine its validity. A recent needs assessment of 119 family members of persons with ABI appears to support several of our themes ( Devany, Kreutzer, and Marwitz, 1992). For example, ninety-eight percent of the respondents said they needed clear information and emotional support, " to have my questions answered honestly," and : "to have a professional to turn to for advice or services when help is needed". A quantitative survey with items derived from our themes could further test the validity and generalizability of our findings. Furthermore, it is important to acknowledge that there was a tremendous amount of variability in parental responses to our questions. Our effort to characterize parental experience in a general fashion may gloss over many individual differences. As briefly noted about one quarter of the parents in this study appeared to have made considerable progress in adapting to their child's condition. These parents expressed very little distress and seemed remarkably positive in the face of a difficult set of challenges. Future research should examine effective coping responses and positive family outcomes in greater detail. Despite these limitations

4.2



## You Can't Imagine

we believe that these parental accounts could be useful in the training of professionals who work with families of persons with acquired brain injury. It is hoped that this study will contribute to generating the understanding and support that parents reported to often be lacking.

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**APPENDIX B**

**Retreat Planning Outline**

## TBI RETREAT PLANNING OUTLINE

### I. Collecting Input from Families:

#### A. Letter Informing Families: (Oct 23)

The success of any retreat weighs heavily on meeting the needs and concerns of those who attend the event. Families can contribute worthwhile information to professionals which will help assure a successful retreat. Six months before the actual event, a letter was mailed to families who had previous contact with our agency through the TBI Home/School Support Project. The letter briefly explained the purpose of the retreat. It also informed the families that someone from ORI would be calling them to collect input that would be helpful to us in planning the retreat.

(See Letter)

#### B. Family Survey:

Two weeks after the letters were mailed, families were contacted by telephone. After a brief introduction, parents were asked if they would be interested in attending a retreat in the near future. If the response was positive, they were asked the list of questions on the Family Survey Form. Separate forms were filled out on each family. Forms were summarized and used to help plan the retreat.

(See Family Survey Form)

### II. Notifying Families:

#### A. TBI Newsletter: (FEB 10)

#### B. Flyer/Registration Form Sent to Families. (March 2)

Flyers and registration forms were sent to the list of families who had received the letters in October regardless of their response to the telephone survey. The flyer provided specific information about the May retreat. The registration form not only requested the basic information (name, address, phone number), but also asked families to check the three topics that were most important to them. Families were requested to return the registration form by the deadline date - March 20.

(See Flyer/Registration Form)

### III. Registering Families for the Retreat:

Registration forms came in almost immediately. The return response was great. Several families called prior to sending their registration form to us, because they were so excited about the retreat and anxious to get their names on the list right away. A list of names was assembled on those families who had sent in registration forms. This list was given to Mona and she used it to put together a registration list for the Inn at Otter Crest.

### IV. Lodging (See Mona)

## V. Class registration:

### A. Consent for Distribution of Names and Addresses

Participants were requested to sign a consent form which would allow their names, addresses, and phone numbers to be distributed among the parents attending the retreat. Every parent at the retreat was willing to give their consent. (I would recommend that during registration the families verify that the information is correct before handing it out to everyone.)

### B. Sign-up for small groups:

Participants were asked to select three small group sessions they would like to attend during the conference. Group size was limited to eight persons. Partners did not have to attend the classes together. This offered couples the choice between attending the sessions separately or three group sessions together. Most couples preferred to attend the sessions together. To help parents remember the groups they had selected, they were encouraged to circle the sessions they had signed up for on their retreat agenda. But just in case they forgot, the final list was given to each small group facilitator.

October 25, 1991

Dear Parent(s):

As you may recall, for the past two years we've been conducting a federally funded project aimed at developing and delivering support services to families of children who've had a traumatic brain injury. In response to some of the issues and needs that have come to our attention, we are planning to sponsor a WEEKEND RETREAT for parents/families of children with TBI sometime in the coming year. The purpose of the retreat would be to provide an opportunity for parents to get to know one another in an informal, relaxed setting while learning some skills and techniques that are helpful in coping with the various after-effects of a child's traumatic brain injury.

Since you're someone with whom we've already had some contact via our TBI Home/School Support Project, we're interested in getting some input from you that will help us in planning this event to be as helpful and enjoyable as possible. This letter is to let you know that you'll be receiving a telephone call in the next few weeks from a staff member named Sandy DeVoogd. We'd greatly appreciate it if you would take a few moments to discuss with Sandy your level of interest in a weekend retreat and to answer some questions regarding convenient times, locations and other preferences you might have with respect to it.

We welcome your ideas in planning this retreat. Once we have contacted a variety of families and have firmed up the details, you'll be receiving an invitation from us to attend it. Thanks very much for your time!

Sincerely,

Elizabeth Cooley, Ph.D.  
TBI Home/School Support Project

TBI WEEKEND RETREAT  
FAMILY SURVEY

Family:  
Phone:  
Address:

1. Would your family be interested in attending a week-end retreat for families of children with traumatic brain injury?

2. Would you like to see the retreat offered to parents only or have it include the entire family?

a. Would child-care be an issue if the retreat was held for parents only?

b. If children were included, what types of issues/concerns would ORI have to know about your child when considering part-time child-care?

3. We would like to offer the retreat some time in March, April or May. Does your family have a preference to the date of the retreat? Do you see a problem with any month?

4. Would you prefer the retreat to be an all day event or an overnight with two days of activities?

a. Friday - Saturday

b. Saturday - Sunday

5. Cost is often an issue for families, would you prefer the retreat to be held at a lower cost facility and financed exclusively by ORI or more expensive facility and the added expense covered by your family?

(How much would you be willing to spend?)

6. We are open to suggestions on possible locations. Does your family have a favorite area in the state that you would like the retreat held?

7. Are there any specific issues or concerns that you would like to see addressed during the retreat?



# Weekend Retreat for Parents of Children/Youth with Traumatic Brain Injury

**Where:** Inn at Otter Crest (on the Oregon Coast)

**When:** Saturday & Sunday, May 2 & 3

**Cost:** \$10 registration fee per person  
(Lodging & 2 meals provided!)

Sponsored by ORI's  
Home/School Support Project

To reserve your space, please send in this registration form  
with the appropriate fee by Friday April 17, to attend.

Tear off

Tear off

## Registration Form

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

Phone \_\_\_\_\_ (Day) \_\_\_\_\_ (Eve.)

Child's name \_\_\_\_\_ Age \_\_\_\_\_ Date of brain injury \_\_\_\_\_

Referred by \_\_\_\_\_

Amount enclosed (\$10 per parent): \_\_\_\_\_

Send to:  
Sandra DeVoogd  
Oregon Research Institute  
149 W. 12th  
Eugene, OR 97405

For more information, call Sandra DeVoogd at 342-8445

Please check the 3 topics that are most important to you.

### Parenting

- Arranging the environment to reduce frustration
- Dealing with emotions & grief
- Childcare issues
- Other: \_\_\_\_\_

### Family

- Reactions of relatives
- Sibling issues
- Financial worries
- Planning for my child's future
- Other: \_\_\_\_\_

### School

- Educational program concerns
- Peer relationships
- Other: \_\_\_\_\_



## ABOUT THE RETREAT

As part of a federal grant, Oregon Research Institute is sponsoring a retreat for parents of students with TBI on May 2-3 at The Inn at Otter Crest in Lincoln City, OR. The retreat format will include brief presentations and small group discussions.

### RETREAT LEADERS

Ellen Lehr, a nationally known expert in the field of pediatric brain injury, will open the retreat with a keynote address, and will participate in the weekend's activities. Other retreat facilitators include: Nancy Hawkins, Charlie Nixon, Elizabeth Cooley, Ann Glang, and Mary Bunch.

Parents will be asked to pay a small registration fee to cover the cost of materials. Lodging and 2 meals are provided at no charge. In addition, stipends for childcare are available for those in need.

### TENTATIVE SCHEDULE

#### *Sat., May 2*

1:00

Keynote address:

Ellen Lehr, Ph.D.

2:00-5:00

Small group topical discussions

6:00-8:30

Dinner, group sessions

#### *Sun., May 3*

9:00

Continental breakfast

9:30-12:00

Group discussions  
and closing

### RETREAT SPECIFICS

**When: Sat., May 2 and Sun. May 3**

**Where: Inn at Otter Crest; Lincoln  
City, Oregon**

**Cost: \$10 registration fee**

BEST COPY AVAILABLE

If you are interested in attending this exciting event send in your registration form immediately. THERE IS LIMITED SPACE AND SLOTS WILL BE ALLOCATED ON A FIRST-COME, FIRST-SERVE BASIS.

# Agenda

5/2-3/92 Otter Crest

## Saturday

1:00-1:15 Introduction

1:15-2:00 Opening Address: Ellen Lehr  
"Coping with TBI from a Family Perspective"

2:00-2:15 Break

2:15-3:15 Concurrent Small Group Sessions (A): [circle the one you registered for]

*Dealing with emotions and grief*

*Effects of TBI on the family*

*Sibling issues*

*Peer relationships*

*Educational program concerns*

3:15-3:30 Break

3:30-4:30 Concurrent Small Group Sessions (B): [circle the one you registered for]

*Dealing with emotions and grief*

*Effects of TBI on the family*

*Sibling issues*

*Peer relationships*

*Educational program concerns*

4:30-6:30 Free Time

6:30 Dinner

7:30-9:00 Informal Socializing

## Agenda (Cont.)

### Sunday

8:30 Continental Breakfast

9:00 Welcome Back: A summary of yesterday

9:15 Large Group Presentation: Mary Bunch  
"Accessing Community Resources"

9:45-10:45 Concurrent Small Group Sessions(C): [circle the one you registered for]

*Dealing with emotions and grief*

*Effects of TBI on the family*

*Sibling issues*

*Peer relationships*

*Educational program concerns*

10:45-11:15 Break

11:15-11:45 Large Group Presentation: Ellen Lehr  
"Planning for Your Child's Future"

11:45-12:00 Closure  
Retreat Evaluations

**APPENDIX C**

**Knowledge Quiz and Teacher Questionnaire**

Knowledge Quiz: Traumatic Brain Injury  
Pick the one best answer.

1. Traumatic brain injury (TBI) most frequently occurs to children between the ages of:
  - a. 1-7
  - b. 8-14
  - c. 15-22
2. Most brain injuries are due to:
  - a. closed head injuries
  - b. penetrating head injuries
  - c. tumors of the brain
  - d. cerebral vascular accidents (e.g., stroke)
3. The most common type of traumatic brain injury occurs when a child:
  - a. falls
  - b. is involved in a motor vehicle accident
  - c. is a victim of child abuse
  - d. drowns
4. Over the past ten years the incidence of TBI in children has:
  - a. increased
  - b. decreased
  - c. stayed about the same
5. Most damage to the brain from traumatic injuries is:
  - a. diffuse
  - b. localized
6. In a traumatic injury, most damage to the brain results from:
  - a. immediate impact (e.g. head hitting object)
  - b. secondary impact (e.g. reaction from the initial impact)
  - c. both
7. The most dramatic spontaneous recovery from TBI occurs within how long following the injury:
  - a. 6 months
  - b. 1-2 years
  - c. 3 years
  - d. none of the above
8. "Moderate to severe" traumatic brain injuries are those in which an individual is comatose for:
  - a. at least 24 hours
  - b. 1-2 weeks
  - c. 3-4 weeks
  - d. over 1 month

9. Children who sustain mild head injuries:
- often have no lasting cognitive or emotional changes
  - may appear "normal" and thus have problems go undetected
  - have not been comatose
10. Children who have experienced traumatic brain injury often exhibit the following kind(s) of behavioral/social/emotional changes following the injury:
- social inappropriateness
  - lack of inhibition
  - depression
  - denial of problems
  - a and c only
  - all of the above
11. Of the following learning characteristics, which one is not typically associated with TBI:
- memory problems
  - consistent low performance
  - poor attention span
  - inconsistent learning rate
12. Children with TBI are usually placed in which type of classroom:
- regular
  - resource room
  - self-contained
  - any of the above settings
13. Most family members have the most difficulty coping with what kind of deficits following TBI:
- physical
  - cognitive
  - personality
  - communication
14. The behaviors of a high school student with TBI who stalks out of the classroom when frustrated, asks a student teacher to go out on a date, and repeatedly asks questions without first raising a hand, most likely represents which of the following?
- deficits in executive functioning
  - disinhibition, or poor impulse control
  - problems with abstract reasoning
  - influence of alcohol or other controlled substances



## Teacher Questionnaire

Please indicate how prepared/competent you feel to meet the needs of student(s) with TBI in the areas listed below. For each item, use the following scale:

- 5 = very prepared
- 4 = somewhat prepared
- 3 = neutral
- 2 = somewhat unprepared
- 1 = not at all prepared
- N/A = not applicable

### Physical Needs:

Feeding	5	4	3	2	1	N/A
Toileting	5	4	3	2	1	N/A
Dressing	5	4	3	2	1	N/A
Transporting	5	4	3	2	1	N/A

### Social/Behavioral Concerns:

Social inappropriateness (e.g. laughing inappropriately)	5	4	3	2	1	N/A
Behavior problems	5	4	3	2	1	N/A
Difficulties with peers (e.g. social withdrawal, alienating others)	5	4	3	2	1	N/A
Emotional problems (e.g. depression, angry outbursts)	5	4	3	2	1	N/A

### Cognitive Concerns:

Language/communication	5	4	3	2	1	N/A
Memory problems	5	4	3	2	1	N/A
Attention span	5	4	3	2	1	N/A
Variability in learning rate	5	4	3	2	1	N/A

Using the same 1-5 scale, please indicate how prepared/competent you feel in carrying out the following activities for your brain-injured student:

- 5 = very prepared
- 4 = somewhat prepared
- 3 = neutral
- 2 = somewhat unprepared
- 1 = not at all prepared
- N/A = not applicable

Interpreting/applying assessment information you've received from others about the student	5	4	3	2	1	N/A
Assessing academic needs	5	4	3	2	1	N/A
Assessing problems in daily living skills	5	4	3	2	1	N/A
Designing an instructional program	5	4	3	2	1	N/A
Implementing an instructional program	5	4	3	2	1	N/A
Evaluating effectiveness of instruction	5	4	3	2	1	N/A
Promoting the student's inclusion in regular education activities	5	4	3	2	1	N/A
Facilitating informal relationships between the student and his/her peers	5	4	3	2	1	N/A

**APPENDIX D**

**Stress Management Manual**