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AUTHOR Glang, Ann; Cooley, Elizabeth; Todis, Bonnie; Stevens, Tuck; Voss, Judith  
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ABSTRACT

This final report describes activities and accomplishments of the Building Friendships project, which developed, implemented, evaluated, and disseminated an intervention to improve the social integration of students with traumatic brain injury (TBI). The project used an ongoing, informal team approach to bring together and mobilize key people in a student's life around the goal of enhancing the student's school- and community-based social network. The project implemented intervention strategies that are both student-centered and environment-centered. These strategies included direct training of students to enhance social skills, training parents in ways to encourage skill generalization, inservice and peer training about TBI, "peer liaisons," facilitation of involvement in school organizations, training staff of community programs, and pairing community volunteers with TBI students. Students, teachers, and family members reported increases in the number of social contacts and overall time spent with nondisabled peers and the average number of reported friends. Individual sections of the report describe the project's context, goals and objectives, conceptual framework, research participants, intervention strategies, logistical problems and modifications, findings, and impact. Extensive appendices include four articles and book chapters resulting from the project, the manual for a video program, and sample newsletter articles. (DB)

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**ENHANCING SOCIAL SUPPORT AND INTEGRATION  
FOR STUDENTS WITH TRAUMATIC BRAIN INJURY**

**FINAL REPORT**

**Project Directors  
Ann Glang and Elizabeth Cooley**

**Co-Investigator  
Bonnie Todis**

**Project Coordinators  
Tuck Stevens  
Judith Voss**

**March 1995**

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ENHANCING SOCIAL SUPPORT AND INTEGRATION  
FOR STUDENTS WITH TRAUMATIC BRAIN INJURY

FINAL REPORT

Severely Handicapped Division  
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Project Directors  
Ann Glang and Elizabeth Cooley

Co-Investigator  
Bonnie Todis

Project Coordinators  
Tuck Stevens  
Judith Voss

March 1995

Teaching Research - Eugene  
99 W. 10th Suite 370  
Eugene, OR 97403

## Abstract

A growing number of children survive traumatic brain injury (TBI) each year and are left with long-lasting alterations in cognitive, physical and behavioral functioning. The growing recognition of this population's needs has led to the inclusion of TBI as a severely handicapping condition under P.L. 94-142. Children who survive TBI are particularly vulnerable to experiencing significant decreases in their social support networks upon their re-entry to school and community, resulting in inadequate integration and community participation opportunities. This reduction in social support and integration is one of the most devastating effects of TBI.

The goals of the Building Friendships project were to develop, implement, evaluate, and disseminate an effective intervention to improve the social integration of students with TBI. The Building Friendships process uses an ongoing, informal team approach to bring together and mobilize key people in a student's life. The focus of the team is enhancing the student's school- and community-based social network. The intervention components are based on techniques that have been empirically validated with students who have other disabilities, and modified to meet the needs associated specifically with TBI. The intervention consists of both student-centered and environment-centered strategies, thus ensuring that the variety of factors contributing to the problem are addressed.

The results of our work on the Building Friendships project suggest that a student-centered team-based approach can make a significant impact on the social integration of students with TBI. Students, teachers, and family members who participated in the project reported increases in the number of social contacts and overall time spent with nondisabled peers and the average number of reported friends. In addition, parents and teachers reported feeling more satisfied with the quality and quantity of the student's social network.

## Table of Contents

i.	Title Page	
ii.	Abstract	
iii.	Table of Contents	
I.	Project Context .....	4
II.	Project Goals and Objectives .....	9
III.	Conceptual Framework .....	9
IV.	Research Participants .....	17
V.	Intervention .....	19
VI.	Logistical Problems and Modifications .....	26
VII.	Project Findings .....	27
VIII.	Project Impact .....	30
X.	Assurance Statement .....	33
XI.	References	
XII.	Appendices	
	A. Articles and Book Chapters	
	B. Building Friendships Manual and Video	
	C. Newsletters (TBI Update)	

## I. Project Context

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).

Traumatic brain injuries often result in severe physical, psychosocial and cognitive problems. However, for the student who has survived TBI, the most devastating consequences are the significant and enduring changes in their social support networks (Begali, 1987; Blau, 1936; Lehr, 1990a). In the following section, we outline the specific problems faced by the student with TBI and the factors that contribute to them. In addition, we highlight the impact of the lack of social support on the student, the student's family and the integration of the student into school and community.

### Factors Contributing to a Decrease in Social Networks

The loss of friends, decrease in social activities, and absence of social support that usually accompany TBI are often the most difficult effects for children to cope with (Lezak, 1987; Oddy, 1984; Singer & Nixon, 1990; Thomsen, 1974; Willer, Allen, Durnan et al., 1990). While the causes of social isolation in students with TBI are many, they appear to fall into three general categories: student-, family-, and school/community-related factors (Goethe & Levin, 1984; Lehr, 1990a) which interact and together form an on-going cyclical process resulting in significant decreases in social networks. In this section, we outline these factors.

#### Child-related factors

Changes in behavior. Social behavior deficits are probably the primary reason students experience decreases in social contacts (Lezak & O'Brien, 1988; Oddy, 1984). By the time a student is school-aged, she or he is expected to function as a group member and act according to the demands of a given social situation (Lehr, 1990a). Yet many students with TBI lose the abilities required to function in social situations. They exhibit behavior often characterized as socially inappropriate (Prigatano, 1986). Students with TBI tend to display a range of maladaptive behaviors including: disinhibition, impulsiveness, decreased frustration tolerance, reduced anger control,

reduced judgement and motivation, and insensitivity to others (Bond, 1984; Brink, Garret, Hale, Woo-Sam, & Nickel, 1970; Goethe & Levin, 1984; Lehr, 1990a; Rosenthal, 1983). Peers and others in the student's environment may be confused by these behaviors and, as a result, the student may be ostracized.

Adjustment to disability. For many students, TBI threatens their developing sense of emotional integrity (Lehr, 1990a). As they realize that the changes are permanent, and that they'll never "be themselves" again, students who experience TBI may become withdrawn or depressed (Lehr, 1990a; Lezak & O'Brien, 1988). Unfortunately, these very understandable emotional reactions to their predicament may only exacerbate the student's ability to form or maintain the social ties that could help them cope more effectively with the situation.

Cognitive deficits. Numerous authors have documented the unique learning needs of students with TBI (Begali, 1987; DePompei & Blosser, 1987; DePompei, Cohen, & Blosser, 1990; Savage, 1987; Savage & Allen, 1987; Ylvisaker, 1985). Students with TBI have problems in the following areas: attention and concentration, memory, new learning, organization and planning, generalization of new skills, and thinking and reasoning (Savage, 1988). Clearly, these deficits negatively impact the child's learning experience. In addition, these deficits may interfere with positive social interactions. A student may, for example, have problems understanding the rules of a game, may forget the directions their teacher gave several minutes earlier, or may be slow to take his/her turn in a card game.

A student's frustration with her cognitive abilities may in turn lead to increased behavior problems in social situations. For example, a student who becomes frustrated with her inability to keep up with peers in a game might become aggressive when another student tells her to take her turn more quickly.

Physical disabilities. A student's ability to participate in social activities may also be restricted because of physical disability. If the demands of a social activity exceed a student's physical abilities, the student may become frustrated and withdraw to a safer environment (Lezak & O'Brien, 1988). Whereas prior to the injury a student's leisure activities involved riding bikes and playing sports, following the injury, activities may center on inactive pursuits such as watching television, playing with a computer, or reading (Lehr, 1990b).

### Family-Related Factors

Family members may also contribute to their injured member's social isolation. As a result of their child's injury, parents' attitudes toward and expectations for their child may change. Rutter et al. (1983) found that,

following their child's injury, parents often became overprotective and feared that many activities were potentially dangerous to their child. Rutter also found that, following injury, parents did more for their child, allowing less autonomy and independence. Willer, Allen, Durnan & Ferry (1990) reported that parental overprotectiveness was perceived as a major barrier by young adults with TBI. While overprotectiveness has been evidenced by parents of children with both mild and severe brain injuries, it is especially prevalent in parents of children with severe TBI.

### School/Community-Related Factors

Individuals in the student's community may contribute further to the student's social isolation. Friends, confused by the student's behavior, may interpret the student's actions as rejecting, and may distance themselves then gradually drift when they realize that these changes are permanent and they cannot help their friend (Deaton, 1987; Lehr, 1990a). This problem is exacerbated by the student having missed, in some cases, an entire year of school while undergoing rehabilitation; the student's age-mates have moved on to a new grade level, establishing new friends and interests.

School personnel, as well as community program staff, may also be confused by the behavioral and cognitive deficits associated with TBI. They may be unsure of how to facilitate interactions between the student his peers, and may have problems integrating the student into school activities (Glang, Cooley, Nixon et al, 1991; Ross, 1990).

In summary, there are a variety of factors that contribute to the lack of social support and integration of students with TBI. We next describe the impact of these deficits on the student's well-being.

### The Impact of a Lack of Social Support and Integration

The decrease in social support experienced by students with TBI is a very serious problem for several reasons. Most salient is the impact on the student's individual well-being, but the decrease in social networks may also impact negatively on the student's family. In addition, a decrease in a student's social support has implications for his/her school experience and community involvement. Taken together, the problems associated with a dramatic decrease in a student's social network represent a potentially devastating blow both to the student's and the family's overall quality of life.

### Effects on the Individual

Many studies have indicated that social support has both a main effect (i.e. a beneficial effect on non-distressed individuals), and an even greater



buffering effect on distressed individuals. Students who experience both the presence and the perception of a supportive social network tend to have higher self-esteem and cope more effectively with difficult situations than do students without such support (Belle, 1989). Conversely, the absence of or a decrease in social support has been associated with a variety of difficulties in both adults, youth and children, including depression and anxiety (Goethe & Levin, 1984; Lezak, 1978; Wolchik, Beals & Sandler, 1989), other psychiatric disorders (Brown et al, 1981), decreased self-esteem (Belle & Longfellow, 1983, 1984), external locus of control (Belle & Longfellow, 1983,1984), and conduct problems (Wolchik, Beals & Sandler, 1989).

Friendships provide a rich opportunity to learn about social functioning and life skills (Meyer & Putnam, 1988) and, as such, are of critical importance to any student's development. This is especially true in school environments, where students are expected to work together in a variety of ways. Students with TBI, who have few friends and poor social networks, are unable to benefit from these kinds of learning experiences. In this sense, the decrease in friendships experienced by students with TBI thus also impacts negatively on the student's overall development.

Given the extreme stresses associated with a traumatic brain injury, the benefits derived from the presence of an adequate support network are especially crucial in the student's adjustment to a major life change. In a study of young males with TBI (Willer et al., 1990), the presence of social support was identified by the young men as one of five primary coping strategies, and was described as "the most essential element in overcoming the limitations imposed by their disabilities" (p. 170).

### Effects on the Family

The loss of childrens' and youths' social support impacts negatively on families as well. Parents of children with TBI and other disabilities may experience demoralization stemming from their child's deficit or total lack of supportive relationships outside of the home (Seaver-Reid, 1986; Singer & Nixon, 1990; Turnbull & Turnbull, 1986). In a series of interviews (Singer & Nixon, 1990), parents of children with TBI consistently mentioned the sadness and helplessness they experienced as they watched their child's previous friendships gradually fade away.

The child's difficulties in maintaining friendships is also related to the practical demands of caregiving experienced by families (Singer & Nixon, 1990). Without the presence of other friends in the child's life, family members become the child's sole source of social support, or may take on the responsibility of orchestrating the child's social life.

As a consequence of this increase in responsibility, both parents and siblings may find it difficult to get away in order to spend time with other people or engage in other activities, thus adding to their fatigue and strain. Siblings of young males with TBI identified the increase in caregiving responsibilities as a key problem, and some even described a feeling of having become "assistant parents" (Willer et al, 1990, p.171).

### Effects on the Child's School Experience

A decrease in social networks also has a negative impact on the quality of the student's school experience. Upon returning to school, the student is often faced with the unpleasant experience of social isolation or rejection by peers. One parent described her son's method of coping with the teasing and other reactions he received from other students: he looked perpetually at the ground "so I don't have to see the expressions on other people's faces when they look at me" (Singer & Nixon, 1990, p. 25).

Lack of social support can also increase the likelihood of the student's placement in a more restricted environment (Kozlowski, Phipps & Hitzing, 1983). That is, social isolation may lead to frustration, depression, and behavioral problems that in turn contribute to the need for a more restrictive placement and a reduction in opportunities for social integration.

### Effects on the Child's Community Involvement

The social isolation experienced by students with TBI often translates to a dramatic reduction in opportunities for participation in community leisure and recreation activities. Following the injury, students with TBI may often engage only in inactive, home-bound activities such as watching television, reading, or playing with a computer (Lehr, 1990b). The need for students with any disability to be fully involved in community activities and society as a whole has been frequently advocated (eg, Laski, 1991), for such integration is an essential element of a person's quality of life. The fact that a lack of social support lessens a student's opportunities for genuine community integration is a serious problem indeed.

### Summary

As described above, the challenges faced by students who survive traumatic brain injury are many. Clinical experience, empirical research and evidence from those most impacted by TBI suggest that, of those challenges, the dramatic decrease in social networks can prove to have a most negative impact on the child's well-being and re-integration into family, school and community life. The project described in the remainder of this report was designed to directly address the social isolation of students with TBI by

developing, implementing, evaluating and disseminating an intervention that trains students in social skills and increases opportunities for students to participate in social and educational experiences via school- and community-based programs.

## II. Project Goals and Objectives

The purpose of this project was to design and implement an effective intervention to support the social integration of students with TBI, drawing on techniques that have been empirically validated with students who have other disabilities. The work was guided by five specific goals:

- 1) To develop a replicable intervention including:
  - a curriculum for teaching social skills to students
  - a teacher guide for teaching and managing student behaviors
  - a parent guide for teaching and managing student behaviors
  - a social network-building procedures guide for school program staff
  - a social-network enhancing guide for parents
- 2) To implement and field-test the intervention in schools using project staff
- 3) To implement the intervention using school staff
- 4) To evaluate the intervention's impact and effectiveness in increasing student social skills and social networks
- 5) To disseminate information about the intervention via presentations and written materials

## III. Conceptual Framework

In the original proposal for this project, the intervention for building social networks for students with TBI included three specific components: a) social skills training, b) school-based social network enhancement, and c) community-based social network enhancement.

These components were initially viewed as complementary, yet separate, emphases. However, as the project evolved it became clear that integration of the three was crucial to achieving a realistic and effective intervention that could be specifically tailored to the unique needs of each student, as well as fit the realities and expectations of individual families,

school staff, and school settings. Our observations and rationale for these revisions to the intervention are outlined in more detail in Section VII of this report.

This section of the final report summarizes the conceptual framework which provided the starting point for developing the intervention. Included are the theoretical and empirical bases for each of the three components to the original model.

### Model Component 1: Social Skills Enhancement Training

The role of social skills in enabling the establishment and maintenance of social support has been clearly documented (Parker & Asher, 1987). An adequate set of social skills gives students access to the important benefits available from social exchanges with peers, teachers, and others in the student's environment. Extensive research has been conducted on the social competencies underlying satisfactory peer relations, social competence, and popularity in both disabled and nondisabled school-age populations (Hollinger, 1987; Parker & Asher, 1987). Social competencies that have been empirically validated across a broad range of studies and shown to be related to both social competence and later developmental outcomes include:

- dispensing and receiving positive reinforcements to/from others
- using appropriate social initiations likely to be accepted by peers
- displaying high rates of positive social behavior toward peers
- thorough knowledge of how to make friends
- good communication skills
- high levels of academic and/or athletic competence
- specialized or unusual skills/attributes that are valued by peers
- low levels of task inappropriate behavior.

The training component requires a double focus. Primary emphasis is on direct training for the students themselves; the secondary focus is on training for parents to support generalization of student skills. The empirical support for both is outlined below.

#### Student Focus: Direct Training to Enhance Social Skills

Researchers have developed a variety of interventions for improving the social skills of students with disabilities (Gresham & Reschly, 1986; 1988). Two of the most effective approaches are: a) direct skills training procedures for increasing students' prosocial repertoire and decreasing their antisocial acts toward peers (Hersh & Walker, 1983; Walker, McConnell, Walker, Clarke, Todis, Cohen & Rankin, 1983), and b) implementing behavioral contingencies to increase prosocial behaviors and reduce maladaptive social behaviors

(Gottman, Gonso, & Schuler, 1976; Gresham, 1981, 1982). Implementation of these strategies have produced improvements in both disabled and non-disabled students' behavioral social repertoires (Barton, 1986).

Social skills training. Social skills training represents a proactive approach to increasing positive and reducing maladaptive social behaviors. The most effective social skills training programs include the following components (Chadsey-Rusch & Rusch, 1987; Cartledge & Milburn, 1983; Goldstein, Sprafkin, Gershaw, & Klein, 1980; Hollin & Tower, 1988; Tower, 1982; Haring, Roger, Lee, Breen, & Gaylord-Ross, 1986; Walker, McConnell, Holmes, Todis, Walker & Golden, 1983):

- a) rationale as to why the social behavior is desirable
- b) direct instruction in using the behavior
- c) opportunities to observe the behavior (modeling)
- d) opportunities to practice the behavior (usually in role-play situations)
- e) feedback regarding performance, and
- f) training for generalization.

Applied behavior analysis. Researchers have reported that the behavior analytic approach is promising for the TBI population because of its structure, repetition, specificity, and consistency (Lewis, Nelson, Nelson, & Reusink, 1988). Through our and others' experiences, we have identified three techniques in particular which are critical for use with TBI students:

1. Directly teach self-monitoring skills. An essential component of adaptive behavior is the ability to monitor one's own behavior. Yet students with TBI often lack this ability, and may need external controls to develop an awareness of their behavior (Deaton, 1987). Our experience in working with one student with serious social behavior problems demonstrates that students with brain injury can learn to monitor their own behavior.
2. Target the underlying intention of the problem behavior. For an intervention to be successful, the underlying intentions of the maladaptive behavior must be addressed (Lehr & Lantz, 1990). Many students with TBI develop maladaptive behaviors because they lack more positive ways to attain their goals.
3. Provide a structured environment. A carefully structured environment can help reduce maladaptive behavior in students with any type of cognitive disability (Grimm & Bleiberg, 1986). For example, a student who understands the steps involved in an academic task will be less likely to become frustrated than if the task is unclear. Since students with TBI have limited information-

processing abilities and may be easily confused (Savage, 1988), providing clear directions and structure is essential. The classroom environment's structure can be increased in a variety of ways including providing verbal cues, encouraging the student to refer to a printed list of tasks, having the student check off each task in sequence as it is completed, and using a timer to help keep the student on task (Cohen, Joyce, Rhoades, & Welks, 1985).

### Parent Focus: Training for Generalization

The ultimate goal of social skills training is to provide students with sufficient social skills to interact positively in all environments. For generalization of social skills to occur, however, parents must be involved in reinforcing the socially adaptive behaviors, and in implementing the behavioral strategies to decrease maladaptive behavior.

Behavioral parent training for parents of children with and without disabilities has been studied widely during the past two decades (Dangel & Polster, 1984; Sanders & Dadds, 1982; Sanders & Glynn, 1981). Parents have been trained successfully to modify aberrant behavior, and to teach a variety of independent living skills to their children with handicaps (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). Parents typically learn to use clear instructions, positive reinforcement, prompting, and non-physical aversives, such as brief time-out.

### Model Components II and III: School-Based and Community-Based Social Network Enhancement

Teaching social skills to students with severe disabilities, including those with brain injuries, is not enough. Rather, environmentally-based interventions are also needed. These interventions include those that impact the integration opportunities afforded the student as well as attitudes of peers and adults toward the student. School-based interventions focus on increasing the student's friendships and social networks at school, to positively effect the student's educational experience. Community-based interventions focus on enhancing opportunities in the student's home, neighborhood, and community.

Although the school and community social support interventions are conceptualized as two different components, the strategies used in each are arrived at through the same process. Effective school- and community-based interventions are based on an assessment of the student's individual social

support needs and the identification of strategies that will directly address those needs.

### The Social Network Enhancement Planning Process

A growing body of literature exists in the area of social support enhancement and integration for students with other types of disabilities: Circles of Support, Circles of Friends, Bridge Building, Personal Futures Planning (PFP) and Making Action Plan (MAPS) (Snow & Forest, 1987; Mount & Zwernik, 1988; O'Brien, Forest, Snow, & Hasbury, 1989; Mount, Beeman, & Ducharme, 1988; Strully & Strully, 1985; O'Brien, 1984).

While the actual processes described in each vary, they all are organized around and exemplified by five primary characteristics:

- 1) The goal is to increase the students opportunities to become integrated into school and the community in a full and meaningful fashion. In others words, mere presence in the setting is not enough; rather, the goal is for child to be meaningfully connected to the people in these settings.
- 2) Through the process the student and significant others are encouraged to set goals that are not limited to those which appear feasible given current resources and programs. Rather, the emphasis is placed on "dreaming" and setting goals that will allow the student to experience a truly normal life.
- 3) The emphasis is placed on the utilization of regular and natural strategies and systems (e.g., peers, regular clubs at school, the student's parents and neighbors) to achieve these goals rather than formal system and organizations (e.g. special education teachers and aides, special recreation programs; case managers).
- 4) To achieve these goals, participants in the process are encouraged to think of and to utilize creative strategies to make these dreams come to fruition and to build these bridges. For example, rather than attempting to increase the social integration of all students with disabilities by starting a peer tutoring program, other strategies aimed at getting a student integrated into existing peer cliques in a school could be used (Gaylord-Ross, Haring, Breen, & Pitts-Conway, 1984). Gaylord-Ross et. al. (1984) provided students with severe disabilities with radios and then taught them to offer to share it with a group of students during class breaks.
- 5) The processes involve identifying specific activities that must be accomplished to achieve the dream or goal, and assigning timelines

and responsibilities to the members of the group. These processes, then, offer a dynamic balance between informal creativity and outcome-oriented structure.

### School-Based Social Network Enhancement Interventions

A review of current literature provides a number of empirically-supported strategies for enhancing a student's school-based social network. Six of these are outlined below.

Peer training about TBI and its effects. Previous research has documented that students who are not disabled often have many questions, fears and misconceptions about their peers who have disabilities (Siperstein, Bak, & O'Keefe, 1988; Rapier, Adelson, Corey, & Crake, 1972; Voeltz, 1980). When a student who has experienced a brain injury returns to school, she or he is often faced with unpleasant peer reactions that stem largely from these unaddressed questions, fears and misconceptions. One strategy often proposed to address these concerns is to educate the student's peers regarding the injury and its potential effects (Ylvisaker, Hartwick & Stevens, 1991). This brief training session takes the form of an informal discussion, and can be conducted by a teacher, parent, staff member, or sometimes even by the child him/herself. In fact, previous research has illustrated that the attitudes of others toward persons with disabilities is more significantly positively impacted when the education is delivered by the person with the disability than when delivered by others (Zollicoffer & Mills, 1981).

Inservice training for school staff about TBI. Just as classroom peers often have a variety of questions, fears and misconceptions about a student with TBI, so too do teachers and other school staff. In addition, school staff members potentially play a key role in facilitating the student's active involvement and participation in educational experiences, so it can be helpful to enlist their understanding and cooperation. An educational presentation to staff members is a commonly cited strategy, both for imparting knowledge useful in the design of instructional programs, and for enlisting help in ensuring that the student has adequate access to a variety of social interaction experiences (Savage, 1987). In some cases, this presentation may consist of a short written overview of TBI along with a verbal description of the student's disability, what to expect, and how to assist him or her. In other cases it may involve more intense assistance including a detailed written and/or verbal description of how to interact with and assist the student to become integrated into the class or organizations activities as well as direct technical assistance to implement the suggestions.

'Peer Liaison' arrangement. Peer tutoring has been used extensively as a strategy to enhance the integration of students with disabilities. There are



well-founded concerns with this approach based on the fact that it places peers in a superior role to the students with disabilities and, thus, may actually hamper rather than foster real friendship formation (Cooley, Singer, & Irvin, 1989). Concern has also been expressed about special friendship programs that pair one peer with a student with a disability. The "special friend" then does a number of activities with the student for a specified period of time. Again, this approach may create a sense a differentness rather than encouraging the formation of real friends.

Sowers & Powers (1991a) have begun to explore an alternative to these approaches which they refer to as "peer liaisons". Using this approach, a peer is asked simply to spend time with the student at school between classes and at lunch for a period of several weeks and to introduce the student with disabilities to other students in his or her clique and in the school. The goal of the "peer liaison" is not necessarily to be a friend to the student, but to introduce the student to others. The student must then take the initiative and responsibility to attempt to make friends with those students s/he chooses. This is the manner in which most individuals make friends in new situations. We get to know one person with whom we may or may not wish to have a real friendship. However, this person introduces us to friends, who in turn introduce us to others. Over time, we meet a few individuals with whom we would like to become friends.

Circle of Friends. Circle of Friends is an approach that is often described as a generic way to plan for an individual's community integration needs. However, some have used it exclusively as a means to bring together the peers of a student and invest them in increasing the social integration and interaction opportunities of a student with disabilities (Wilson & Roggow, 1989). A group of peers is brought together and asked to identify specific ways they can help the student with TBI to be accepted by other students and to make friendships at school. The group may also be asked to extend their assistance to the student to community settings.

Integrate the student into existing cliques. As suggested earlier, one approach used to increase the social networks of students with disabilities is to give them strategies that they can use to enter informal cliques in schools. Cliques are groups of students who in contrast to a formal club or organization, simply choose to associate together between classes, and before and after school. A number of different approaches have been documented as successful in integrating students with disabilities into these groups, including providing the student with means of facilitating their acceptance (Gaylord-Ross et. al., 1984).

Facilitation of involvement in school organizations. A commonly used approach to increasing the social integration of students at school is to

assist them to join and participate in formal school organizations such as service clubs and sport teams (Wilcox & Bellamy, 1984).

### Community-Based Social Network Enhancement Interventions

School is a critical part of most students' social lives and serves as the place where most friendships are formed. However, the community also offers students many opportunities for friendship-building and social activities. A review of current literature documents a variety of community-based interventions to support the social integration of students with TBI. Three of these are outlined below.

Parent training in arranging social opportunities. Parke & Bhavnagri (1989) offer a useful framework for viewing the ways in which parents can influence their child's social relationships -- they distinguish between direct and indirect means of influence. Inasmuch as the nature of interactions between a parent and child reinforces either appropriate or inappropriate social behaviors, the parent is viewed as indirectly influencing the extent to which the child is capable of forming social ties outside of the home. It is this type of parental influence that was targeted by the Social Skills Training component above, in that the training focused on the parent as an agent of generalization in the child's newly learned social behaviors.

In contrast, the parent training referred to in this component focuses on the direct role parents can play as managers of their children's social activities. That is, parents' assistance can be enlisted as arrangers of their child's social opportunities; they can play a critical role in organizing play groups or enrolling their child in various neighborhood activities (Rubin & Sloman, 1984). They can also identify clubs such as the Boy or Girl Scouts and volunteer to serve as leader or to assist in arranging for their child to join one.

Training for staff of community programs. Staff employed by community recreation facilities and programs may often feel unprepared or ill-equipped to meet the needs of students with disabilities, and so may inadvertently or overtly exclude them from valuable opportunities for community integration. For example, the staff of a local Big Brother/Big Sister program told us that they had not attempted to pair volunteers with children with disabilities because they felt ill-equipped to provide adequate training to the volunteer. The provision of information and assistance to community program staff can support their efforts to more fully integrate children with disabilities into specific activities.

'Fostering Friendships' volunteer program. Cooley (1986, 1989) successfully implemented a program that paired community members

(mostly university students) with students with a variety of disabilities, including TBI, for the purposes of forming mutually fulfilling friendships and providing the students with additional opportunities for community participation. While it is recognized that such a program is not sufficient in and of itself in enhancing a student's social network, it is one of a variety of options that contribute to the integration of students with disabilities into the community. Care is taken in this program to recruit only those volunteers who value reciprocity in the relationship with the student. That is, college students desiring to be paired with a student solely for the purpose of receiving academic credit, or who see themselves as doing the student "a favor", are deliberately excluded from participating. The aim, then, which may at first glance appear somewhat peculiar, is to foster informal friendships via a formal program. "Nevertheless, until students with disabilities no longer experience a deficit in naturally-occurring relationships, formal programming for such support may be a necessary step toward more complete community integration" (Cooley, Singer & Irvin, 1989, p. 208). This strategy may be particularly useful for older students who are close in age to college students and young adults who are out of school.

#### Summary

The conceptual framework described above provided the foundation for the work of this project: the development and implementation of an effective intervention to support the social integration of students with TBI. The next section of the report summarizes that intervention.

#### IV. Research Participants

Across both phases of this project, a total of 22 students with TBI participated in the Building Friendships process (see Table 1 below). Seven of these students did not complete the entire process. Reasons for withdrawal included: 1) student developed a medical condition that required hospitalization; 2) student and family moved from the school/area; 3) school staff changes resulted in school sites withdrawing from the project; and 4) while parents consented to the student's participation, the school chose not to participate.

Table 1. Participants with ABI in the Building Friendships Project.

Name	Age in Years	Age at onset	School setting	Type of injury
* Allen	13	10	Suburban	MVA
* Shawn	13	7	Small town	Brain tumor
* Mary	19	14	Small town	Anoxia secondary to attempted hanging
* Carol	16	15	Small town	Brain tumor
* Jen	8	5	Small town	Pedestrian-MVA
* Chuck	17	17	Urban	Pedestrian-MVA
* Lowell	13	11	Rural	Anoxia secondary to asthma attack
* Kim	12	1	Rural	Fell off horse
* Tia	18	9	Rural	Bicycle-MVA
** Sarah	9	2	Rural	Abuse
** Elise	9	infant	Rural	MVA
** Mike	12	7	Rural	MVA
** Matteo	11	7	Rural	Bicycle-MVA
** Joachim	15	11	Urban	Pedestrian-MVA
** Jerry	8	3	Rural	MVA
Trish	13	7	Suburban	MVA
Don	16	15	Suburban	MVA
Judy	8	6	Suburban	Pedestrian-MVA
Charlene	20	17	Urban	Anoxia secondary to cardiac arrest
Barb	17	15	Urban	Self-inflicted gunshot wound
Rita	19	unknown	Small town	MVA
George	11	8	Urban	MVA

\* Phase I

\*\* Phase II

Remaining: Incomplete data set

Abbreviation: MVA, motor vehicle accident.

Note: All of the names are pseudonyms.

### Phase I Participants

During phase I of the project, the Building Friendships process was facilitated by project staff. Empirical findings are based on nine students who participated during this phase. Of the nine, five were boys and four were girls, ranging in age from 8 to 18 (mean age = 14.3). Prior to their injury, seven of these students were average to above-average students who attended their home schools, performed at grade level, and were not described as displaying behavior problems. The remaining two were preschool age when they were injured. According to parents' reports, none of these students showed signs of physical, behavioral, or cognitive deficits prior to their injury.

When they became involved with the Building Friendships project, these students averaged 4.4 years postinjury recovery (range = 0 - 11 years), well past the most rapid period of "spontaneous recovery." As a result of their injuries, they experienced significant deficits in physical, cognitive, and behavioral functioning. They received special education services in resource or self-contained settings. All of the students had experienced a significant decline in their social network. They described themselves as having few, if any, friends.

### Phase II Participants

During Phase II of the project, the Building Friendships process was facilitated by staff at the individual schools. Seven students participated in the full cycle of the team process during this phase. Of the six, three were boys and three were girls. Ages ranged from 8 to 15 years, with a mean age of 10.7 years. This group averaged 5.5 years postinjury, with a range of 3 to 9 years.

## V. Intervention

This section of the final report 1) provides a description of the Building Friendships process, and 2) briefly outlines the two phase implementation of the process.

### The Building Friendships Process

This project focused on alleviating the social isolation experienced by students with TBI by developing and enhancing school-based social networks. Project staff used an adapted version of MAPs for this purpose (Vandercook et al., 1989). The overarching goal of the Building Friendships process is to increase the quality of the student's social life through an ongoing, informal

team process designed to bring together and mobilize key people in a student's life.

This section provides a brief description of the intervention, including the four phases of the process, the steps involved in the initial team meeting, and a menu of strategies used to guide program planning for individual students. Additional details on the Building Friendships process are provided in Cooley et al., 1997, and Sowers et al., 1996, included in Appendix A of this report.

### The Four-Phases of the Building Friendships Process

The Building Friendships process, like MAPs, represents a dynamic and fluid person-centered planning strategy to increase the ability of students and families to guide their own solutions to problems of social isolation. The student, family, peers, and professionals participate in a four-phase process:

- I. Gather information through interviews with the student, parents, school staff and peers. Project facilitators conduct interviews to identify opportunities within school and community settings to create new friendships, to enhance current friendships, and to develop increased social opportunities. This information is used as a basis for the initial team meeting.
- II. Recruit family members, school staff, and peers to be team members. Based on information gathered in interviews, key individuals are identified and invited to the initial meeting. The student and family members play the primary role in determining whom to recruit. Facilitators are responsible for making contact with potential team members, who must include peers, extended family, and school staff. In some cases, whole classes are given information about the purpose for developing the team, and interested peers are asked to participate.
- III. Conduct an initial team meeting to share information and to create visions for the future. The team identifies individualized social goals and specific strategies to meet these goals.
- IV. Hold regular review meetings. Every 2-3 weeks, team members meet to review progress, revise plans and strategies, and reevaluate team membership and responsibilities.

## The Initial Team Meeting

Whereas MAPs addresses a full range of student-centered issues, the Building Friendships process focuses solely on social issues and thus requires less time. The seven steps of the initial team meeting are guided by specific questions, as outlined below.

1. Who is (the student)? Participants are encouraged to offer as many words and phrases as they can think of to describe the positive qualities and attributes of the student. These are shared out loud and recorded by the facilitator in colorful markers on a large sheet of paper. This first question sets the tone for the rest of the initial meeting in its upbeat focus on the student's strengths. Importantly, this step can also be emotionally charged for students and families unaccustomed to such an outpouring of positive feedback.
2. What are your hopes and dreams for (the student)? The focus here is on the social domain. The student is given the opportunity to state his or her own hopes and dream first. The facilitator checks with the student frequently to make sure that the hopes and dreams offered by other team members are acceptable. The student is the only one who holds veto power here. As long as the student accepts a hope/dream offered by another, the response is recorded and nothing is censored. This serves to model a mindset that both empowers the student and expands the team's notion of what is possible. Important goals for the student often emerge from dreams which, initially, might seem unrealistic to achieve.
3. Who is in (the student's) current 'circle of friends'? With the information previously gathered, a pre-prepared visual diagram is presented to the group to represent the key people currently in the student's life. This diagram consists of four concentric circles, with the student's name placed inside the innermost circle. Those closest to the student, trusted friends, acquaintances, and paid professionals are all listed on successive circles extending outward from the student. The intent of this activity is to graphically demonstrate the nature of the student's social network. In most cases, students with TBI have only a few close and trusted friends and an abundance of acquaintances and paid professionals in their circle. The goal of the Building Friendships process is to create positive social changes to allow expansion of the student's inner circle of trusted friends.

4. What are the goals for the student? The next phase of the first meeting involves identifying several goals toward which the team can begin working. Often these goals are derived from the hopes and dreams created earlier by the team. As in the earlier steps of the process, the student decides whether chosen goals are acceptable. Goals are fluid and can be changed as needed, and it is important to remind the group that more goals can be added in future meetings.
5. What are the obstacles to goal attainment? Next the team identifies obstacles to achieving the identified goals. Team members are asked to think of all the reasons why the identified goals are not currently being addressed.
6. What specific strategies will be used to attain goals? Every student with TBI is unique. Therefore, the activities and strategies decided on will vary considerably from person to person. Pushing the limits of commonly accepted practices is encouraged to facilitate the emergence of creative, untried approaches and solution.
7. What is the action plan? Goals and strategies are then prioritized into an action plan consisting of three columns: what, by whom, and when. This plan keeps members clear on tasks and accountable for follow-through.

### Menu of Strategies

The menu of strategies shared with the team is meant to be a starting point for discussion and creativity in addressing the unique needs and goals for each student. These might include:

- modifying student's schedule to increase social opportunities in inclusive settings;
- presenting information about TBI to peers, including specifics about the student who is the focus of the team's planning
- organizing recreational activities linking the student to existing community activities
- forming friendship clubs to shift the focus from one to many students
- developing a buddy system for getting to and from class, to lunch and recess
- utilizing cooperative learning activities in the classroom
- planning social events outside of school
- creating organizational systems for keeping track of important information



- offering classwide disability awareness and community building activities
- facilitating involvement in extracurricular school functions.

Examples of the use of these strategies with individual students during the course of the project are summarized in Cooley et al., 1997, and Sowers et al., 1996 (see Appendix A).

### Phase 1: Development and Implementation of Intervention by Project Staff

While the Building Friendships process drew heavily on existing approaches (ie, MAPs and Circle of Friends), the combination of these approaches, their application to students with TBI, and the focus on enhanced social networks in schools were new. The intent was to allow a cycle of implementation, evaluation, revision and refinement leading to a workable intervention for use by school-based personnel. Project staff served the primary roles of facilitators for Phase 1 of the work.

After recruiting school sites for the project, staff met by phone or in person with key participants at each site, including the student, the parent(s), and the student's primary teacher. During these contacts, project staff explained the purpose of the project, provided a general orientation to the Building Friendships process, determined participants' interest and willingness to be involved, and completed consent forms and initial measures. At this time, students, parents and teachers were also asked to suggest others (eg, peers, teachers, family members) who might participate as members of the student's team.

Project staff then made the necessary contacts to complete each team and worked with each group to schedule the first team planning session. During that first meeting, the project facilitator walked each group through the seven step process, building in flexibility to meet the unique needs of each student and team. Each team completed the process and produced a plan for the student including goals, strategies, individual accountability and a clear timeline.

At subsequent meetings, the project facilitator guided the group through a review of the plan to document what had occurred, assess progress and identify next steps. Between meetings project staff maintained informal contact by phone with team members as needed to support their efforts.

Each team met roughly monthly for a 4 to 6 month period until the end of the school year. The final team meeting included an optional brainstorming process to identify activities to support continued social opportunities for the student during the summer months.

## Phase 2: Replication of Intervention by School Staff

Phase 2 of the project focused on implementation of the Building Friendships process without the assistance of outside consultants.

Recent work in the field of special education suggests that interventions that take into consideration the school context and the variety of competing demands faced by school-based personnel are more likely to be adopted by schools (Ylvisaker & Feeney, 1995). Several features of the intervention--familiarity with the student and peers, in-depth knowledge of the school's policies and culture, and the need for close monitoring and communication among students, teachers and parents--indicated that implementation by an on-site educator would be highly advantageous. Implementation by on-site staff has the added benefit of increasing the capacity of practitioners to meet the needs of students with disabilities in a highly individualized, systematic, and effective way.

Facilitator training. Seven pairs of facilitator and student participants were recruited through a statewide notice to educators about a research project aimed at expanding the social networks of students with TBI. (See Section V of this report for a more detailed description of the subjects for this phase of the research.) Friendship Facilitators attended a day-long workshop on the Building Friendships process coordinated by the investigators. Following a presentation about social issues specific to students with TBI, the facilitators learned the steps involved in using the Building Friendships process, as well as a variety of specific strategies for increasing a student's social involvement. Training formats included didactic presentation, videotape, and role-play. Each of the facilitators had an opportunity to practice using the skills presented and receive feedback from the presenters. Facilitators also learned specific data-deeping procedures to document group activities.

The investigators maintained weekly telephone contact with each of the facilitators throughout the study. Topics of discussion included how to deal with behavioral issues, helping the students' families problem-solve conflicts that arose between the students and their friends, and how to diminish adult intervention and encourage the peer group to plan activities independently.

Implementation. Although each facilitator followed the four-phase process, the specific nature of each implementation varied because it was tailored to each student, team, and school context. In each case, the facilitator met briefly with the student, his or her parents, and at least one key educator to determine the nature of the student's current friendship network. The facilitator then recruited between four and eight team members. Over the

course of the study, the core friendship team for each student consisted of the student, parent, facilitator, and at least one peer, with additional members (eg, coach, additional peers, siblings) attending when possible.

At the initial team meeting, the team followed the predetermined seven-step agenda to develop a specific action plan that addressed the student's goals. Ongoing team meetings with the core team members occurred every 2 to 3 weeks over a 3 to 4 month period.

### Evaluation

In both phases of the project, pre-post quantitative data were collected from parents, students, and teachers. Outcome measures included the following instruments:

**ACCEPTS Social Skills Assessment** (Walker et al., 1983): used to assess student social skills in school settings..

**School and Community Activity and Integration Assessment** (Sowers & Powers, 1990): this instrument assesses a student's performance of functional activities in school and community settings, the number and type of peer socializations the student engages in on a routine basis, and the student's participation in socialization opportunities including recreational and leisure activities. The measure is administered to a parent for home and community activities and to a teacher for school activities.

**Social validation indices:** An intervention may be shown to be effective as measured by objective parameters. However, unless the consumers of the intervention perceive it as effective and worthwhile given the effort required for implementation, it is unlikely that the intervention will be utilized. Three measures were developed to assess the participants' perceptions of the model. These measures were administered pre-post..

1. Parent Effectiveness Rating. This instrument will be developed to measure the extent to which parents perceive that their child improved their social skills and increased their social networks as a function of their participation in the project.
2. Student Effectiveness Rating. This instrument will be developed to measure the extent to which the students perceive that their social skills and social networks have improved through their participation in the project.
3. Staff Effectiveness Rating. This measure will ask school staff to indicate the extent to which they believe the student's social skills and networks have improved through as a result of the project.

During Phase II, the research design was expanded to include single subject and qualitative methodologies. The single subject study, conducted with 3 facilitator/student pairs, is described in detail in Glang et al. (1997) (see Appendix A).

Qualitative evaluation. A graduate student trained in qualitative methodology conducted participant observations for 4 of the Phase II students over a five-month period. Each student was observed approximately once a month for about three hours each time. The observations sampled different parts of the school day and provided qualitative data on rate and quality of social interaction across a variety of school settings. Observations also included Building Friendships meetings for each of the students, including a transition meeting for one student who was moving from elementary to middle school. Because the participant observer became a familiar presence in each of the schools she was also able to conduct informal interviews with teachers, friendship facilitators, students, and in some cases, target students.

These conversations, as well as detailed accounts of the observations, were recorded in field notes. The notes were read by all project staff. Themes within each case and similarities and differences across cases were discussed at staff meetings. These tentative findings were tested in subsequent observations. Dr. Todis coded the data by theme and broad categories, then prepared a case study for each student, comparing themes and categories across cases.

The qualitative findings helped answer some of the questions that arose from the single subject study, e.g., what factors that are not readily accessible for quantitative assessment account for decreases in student satisfaction, lack of maintenance of social contacts, and differential success of the intervention for different students? Together the single subject study and the qualitative data provide a clear view of how the Building Friendships process can promote social integration for students with TBI and factors within public schools that are likely to constitute barriers to implementing the process most effectively.

## VI. Logistical problems and modifications

Over the course of the three year project, we made modifications to the proposed project in three areas: integration of the social network enhancement intervention, research design, and an increased emphasis on school-based implementation. We describe the changes made in each of these areas below.

Integrated approach. Our original conceptualization of an intervention to increase social networks for students with TBI included three specific components: a) social skills training, b) school-based social network enhancement, and c) community-based social network enhancement. Each of these components would be delivered in a logical order, using separate curricula and processes. As we began working with schools however, it

became clear that a fragmented approach involving multiple staff, curricula, and separate meetings was inefficient and unrealistic. Instead, the complex needs of the students we worked with called for an integrated, highly individualized approach. The core Building Friendship team, composed of the student, parent, key educator, and facilitator was capable of implementing such an approach. Drawing from a comprehensive menu of strategies, the team selected strategies and devised an action plan that addressed a wide range of problems (e.g., problem behaviors, lack of opportunity for social contacts in the community, organizational and memory deficits that inhibited social interactions).

In some cases, the team's meetings were also used to address issues about school programming that were not directly related to the concerns about social isolation. In this way, the Building Friendship process became a complimentary part of the school's normal organizational and communication structure, and was more readily received by the schools we worked with.

Research design. Our original proposal called for a group study to evaluate the effectiveness of the social network enhancement intervention. This approach was unrealistic for several reasons. The heterogeneity of the population of students with TBI makes any findings based on group comparisons highly problematic. Single subject methodology is much better suited for evaluating the effects of an intervention on students with TBI, whose characteristics (e.g., severity of injury, pre-injury history, family support) are so diverse. Similarly, we found that pre-post quantitative measures were inadequate for studying the complex and rapidly changing nature of social interaction. What was needed was ongoing measurement that could detect the subtle changes that took place as a result of the Building Friendships intervention. The addition of single subject and qualitative methodologies allowed us to study this on-going change process.

Emphasis on school-based implementation. The overarching goal of a research project such as this one is to develop strategies and materials that can be used easily in school settings. In our original proposal, we planned to 1) develop, evaluate, and refine the Building Friendships intervention using project staff as facilitators, 2) develop materials, and 3) provide educators with these materials so that they could implement the process in schools with minimal project support. After Year 01, we realized that any materials based on the experiences of outsiders (ie; project staff) lacked validity and generalizability. A necessary intermediate step involved training facilitators in the Building Friendships process, collecting information about their experiences, and refining materials based on this information.

## VII. Project Findings

This section provides an overview of project findings. Specifically, it includes: 1) highlights of a state-wide survey of educator's perceived

knowledge of and competence with programming for students with TBI; 2) a brief summary of empirical results of pre and post measures administered to students, parents and teachers; and 3) an outline of major observations gleaned through the implementation process.

### Educator Survey

For the educator, the student with TBI presents a complex constellation of needs. More importantly, educators' lack of awareness of the effects of TBI can interfere with effective delivery of services for students (Rosen & Gerring, 1986; Todis & Glang, 1994). 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. These workshops provided an opportunity to assess perceptions of Oregon educators as to their knowledge of and competence with education for students with TBI. A total of 183 participants completed the survey. The group included both general and special education teachers, speech/language therapists, support service professionals (eg, school psychologists, occupational therapists, school nurses), and school administrators.

Respondents scored moderately low on the measure of knowledge (mean score = 71%). These educators also reported only moderate levels of perceived competence for meeting these students' behavioral, academic, social and cognitive needs (mean ratings between 2.9 and 3.3 or "somewhat prepared"). (See Glang et al., 1996, in the Appendix X of this report for more detail.) Educators rated themselves lowest in the area of social behavior. The survey provided valuable information about educators' need for specific interventions to help students with TBI to develop and maintain social networks.

### Empirical Results

Project results support the effectiveness of the intervention -- the Building Friendships process -- in enhancing the social integration of students with TBI. Pre- and post-assessment measures revealed increases in:

- the number of social contacts and overall time spent with nondisabled peers
- the average number of reported friends
- parents' and teachers' satisfaction with the quality and quantity of the student's social network, and
- students' overall confidence and positive feelings about school.

These positive results are tempered, however, by several findings and observations:

- 1) for at least two students, reported satisfaction with social integration actually decreased, possibly due to increased awareness of social isolation;
- 2) increases in students' social contacts were not consistently maintained over time once the student moved on to the next grade and school personnel discontinued their involvement;
- 3) there is differential agreement among families over what constitutes adequate social support and the extent to which social vs. academic issues should be the focus in school settings; and
- 4) school personnel have differing levels of interest in and/or availability for enhancing students' social opportunities.

These and other project findings, observations and conclusions are presented in greater detail in Glang et al., 1997 and Sowers et al., 1996, in Appendix A of this report.

#### Observations Based on Implementation

Staff observations and field notes resulted in a number of observations key to the successful implementation of the Building Friendships process. Included are the importance of:

- 1) tailoring the approach to the unique needs of the individual student;
- 2) emphasizing reciprocity in friendships;
- 3) ensuring the process is student driven;
- 4) securing visible support from the building principal; and
- 5) enrolling at least one committed adult to facilitate the overall process.

These and other observations are discussed in more detail in Cooley, Glang, & Voss, (1997); Sowers et al., (1996); and Glang et al., (1997), included in Appendix A of this report.

## VIII. Project Impact

Overall impact of a project such as Building Friendships goes well beyond the specific measured results with the research subjects themselves. The degree to which the project has an impact on the field -- both current practice and future research -- is dependent upon the quantity and quality of dissemination efforts. This section of the report summarizes the dissemination activities of this project, including publications, presentations, and professional development opportunities.

### PUBLICATIONS

#### *Articles and Book Chapters*

Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with ABI: A school-based intervention. Journal of Head Trauma Rehabilitation 12(2), 32-47.

Glang, A. & Todis, B. (1997). Providing ongoing support to educators through team-based consultation. In Glang, A. Singer, G.H.S., & Todis (Eds.) . Children with Acquired Brain Injury: The School's Response. Baltimore: Paul H. Brookes.

Todis, B., Glang, A., & Fabry, M. (1997). Family, school, child: A qualitative study of the school experiences of students with ABI. In Glang, A. Singer, G.H.S., & Todis (Eds.). Children with Acquired Brain Injury: The School's Response. Baltimore: Paul H. Brookes.

Cooley, E., Glang, A., & Voss, J. (1997). Making connections: Helping children with acquired brain injury build friendships. In Glang, A. Singer, G.H.S., & Todis (Eds.) . Children with Acquired Brain Injury: The School's Response. Baltimore: Paul H. Brookes.

Sowers, J.A., Glang, A., Voss, J., & Cooley, E.A. (1996). Enhancing friendships and leisure involvement of students with traumatic brain injuries and other disabilities, in Powers, L.E., Singer, G.H.S., & Sowers, J., (Eds.). Building self-competence among children with disabilities. Baltimore: Paul H. Brookes.

Glang, A., Todis, B., Moore-Sohlberg, M., & Reed, P. (1996). 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.

#### *Newsletter*

TBI Update, October 1994. "Current educational services for students with TBI: The parent perspective." Teaching Research, Eugene, OR.



TBI Update, June, 1995. "Building friendships: A school-wide effort to expand Joey's social networks." Teaching Research, Eugene, OR.

#### PRESENTATIONS AT NATIONAL CONFERENCES

Todis, B., Glang, A. & Fabry, M. A "C" for Mike is an "A" for anyone else. The Association for Persons with Severe Handicaps. New Orleans: November, 1996.

Glang, A. & Kerns, K. Intervention strategies for school-age children with cognitive deficits. Invited Speaker, Nelson Butters West Coast Neuropsychology Conference. San Diego, CA: April, 1996.

Todis, B. & Glang, A. Educating students with traumatic brain injury: Issues and strategies. National Head Injury Foundation. Chicago, IL: November, 1994.

Cooley, E. & Glang, A. From isolation to integration: Facilitating school re-entry and inclusion of students with traumatic brain injury. Council for Exceptional Children. Denver, CO: April, 1994.

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. Facilitating social integration in school and community settings. 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.

#### PRESENTATIONS AT STATE AND REGIONAL CONFERENCES

Glang, A., Cooley, E., Voss, J., & Miller, B. Fostering peer relations: Update on Oregon Research Institute's Building Friendships Project. Invited speakers, Oregon Head Injury Foundation, Salem, Oregon: October, 1993.

Cooley, E., Glang, A., Miller, B., & Voss, J. Enhancing social support for students with traumatic brain injury. Presented at the Oregon Association for Retarded Citizens Convention. Eugene, OR: May, 1992.

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

#### CURRICULUM MATERIALS

Voss, J. Stevens, T., Glang, A., & Cooley, E. (in press). Building Friendships: Facilitating social integration of students with TBI. Video/manual package.

## INSERVICE AND PROFESSIONAL DEVELOPMENT ACTIVITIES

Project staff gave the following inservice presentations on the Building Friendships process to multi-disciplinary teams:

Pendleton, Oregon (Umatilla-Morrow Educational Service District):  
March 17, 1996 (25 participants)

Eugene, Oregon (Lane Educational Service District): March 11, 1996 (30  
participants)

Medford, Oregon (Jackson Educational Service District): April 7, 1995  
(18 participants)

Portland, Oregon (Portland Child Services Center): January 30, 1995 (20  
participants)

## 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 Brain Injury Association' Education Department.

## XI. REFERENCES

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**APPENDIX A: ARTICLES AND BOOK CHAPTERS**

# Making Connections

## Helping Children with ABI Build Friendships

Elizabeth A. Cooley,  
Ann Glang, and Judith Voss

I guess the biggest disappointment was when his friends found out it was more of a permanent situation, and they just kind of faded away from us. . . . They just stopped coming around, didn't see him anymore, and that was kind of heartbreaking.

Parent of a child with ABI (Singer & Nixon, 1996, p. 40)

### ACQUIRED BRAIN INJURY AND SOCIAL ISOLATION

Children and youth who survive acquired brain injury (ABI) are often left with severe and lasting physical, cognitive, and emotional difficulties. Perhaps the most devastating of these changes for the student with ABI is the loss of friends and the decrease in social activity that typically accompany such an injury. Because of the frustration, anger, loneliness, and reduced self-esteem that these changes usually bring, the other problems and challenges associated with ABI are frequently compounded. Lacking a network of supportive friends, the child with ABI often loses confidence in his or her ability to succeed in school and the community.

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45



causes of social isolation in students with ABI are many and unrelated. A brain injury brings with it emotional, behavior, and cognitive changes for the child. Some of these changes, which are a direct result of the injury itself, may in turn affect the way that other people react to and relate to the student, which consequently may contribute further to the child's difficulties. Following are some of the most common factors contributing to the social isolation frequently experienced by students with ABI.

#### Emotional Changes

ABI is an irreversible life change to which adjustment takes time and effort, and for many students with ABI, this adjustment is troublesome. As they realize that certain changes are permanent and that, in some ways, they will never be "themselves" again, students with ABI may become withdrawn or depressed (Garske & Thomas, 1992). Unfortunately, these very understandable emotional reactions may further isolate the student, making it difficult for him or her to develop and maintain the very friendships that could help him or her to cope more effectively with the stressful aftereffects of the injury.

#### Behavior Changes

Following a brain injury, the student's ability to handle social situations may dramatically decline. Ordinary interactions that once were easy may become much more difficult (Fletcher, Ewings-Cobbs, & Minor, 1991). He or she may begin to act differently, often displaying a lack of inhibition, decreased judgment, verbal aggression, an inability to read subtle social cues, insensitivity to others, and/or a lack of confidence (Dywan & Segalowitz, 1996). Peers may wonder, for example, what happened to their friend's sense of humor or why he or she uses embarrassing language. Because of the peers' confusion about or intolerance of these behaviors, the student may become ostracized. The ensuing social isolation can have an enormous impact on the self-esteem and psychological well-being of the student with ABI, who in turn may engage in even more negative behaviors in an attempt to get attention. Thus, in many cases, the child with ABI may find him- or herself virtually friendless and alone except for family members and paid service providers.

#### Cognitive Changes

The cognitive impairments associated with ABI may also negatively affect the student's social network. Some characteristic learning problems of students with ABI include problems with attention and concentration, poor memory skills, unpredictable and uneven learning progress, problems becoming and staying organized, difficulties

with problem solving, and a tendency to become easily overloaded or fatigued (Vieth, Johnstone, & Dawson, 1996). A student's frustration with his or her cognitive abilities may lead to increased behavior problems in social situations. For example, a student who becomes frustrated with her inability to keep up with peers in a game might become aggressive when another student tells her to take her turn more quickly.

Other students may subtly or directly exclude a student who has problems keeping up with or tracking the flow of ideas in a conversation. Academic achievement may also decline, which may then lead to a more restrictive school placement in which opportunities for exposure to age-appropriate social situations are more limited.

#### Physical Changes

Many social activities (e.g., recreational sports) are physical in nature. A student's ability to participate in physical leisure or social activities may be limited by physical restrictions, fatigue, or depression-related apathy as a result of the injury. The student may then turn to more inactive, socially isolating pursuits (e.g., television, computer and video games), and social opportunities subsequently decrease.

#### Family Factors

In some cases, family members may unknowingly contribute to the child's social isolation. Following an injury, parents' attitudes toward and expectations for their child may change. Some parents may become more protective, emphasizing and fearing the potential dangers inherent in almost every activity (Sokol et al., 1996). And given that students who have already had one brain injury are indeed at greater risk for a second injury, parents' fears are not unfounded. Striking a balance between caution and acceptance of the everyday risks that are part of growing up can be very challenging for parents of children with ABI.

#### School-Related Factors

The school community may further contribute to the student's social isolation. Friends at school may be confused by the student's behavior and may even view the student's actions as offensive. The student's friends may be unsure of how to relate to the student following the injury. Without support for their own confusion and emotional reactions, these friends may eventually drift away. This problem is compounded by the fact that students with ABI have, in most instances, been absent from school for a lengthy period of time. In the meantime, friends may have moved ahead a grade, made new

developed new interests. Consequently, the student with ABI must face the prospect of reentering social and peer relationships that may have changed with the passage of time. Having lost many peer role models, the student's opportunities to relearn appropriate social behaviors from friends is diminished.

#### THE LACK OF SOCIAL SUPPORT AND INVOLVEMENT

The decrease in social support experienced by students with ABI is a very serious problem for several reasons. Most salient is the impact it has on the student's own well-being, but the decrease in social networks may also have a negative impact on the student's family. In addition, a decrease in a student's social support has implications for his or her school experience and degree of community involvement. Taken together, the problems associated with a dramatic decrease in a student's social network represent a potentially devastating blow to both the student's and the family's overall quality of life.

#### Effect on the Student

Many studies have indicated that social support is important, even crucial, to the psychological and physical well-being of adults (Cohen, 1988; Cohen & Wills, 1985). These studies have demonstrated that social support has both a *main effect* (i.e., a beneficial effect on individuals without life stressors) and an even greater *buffering effect* on individuals with life stressors. The same holds true for students. Numerous studies have reported this buffering effect of social support on students who have experienced severe life stressors (Cowan & Work, 1988; Garmezy, 1983; Sandler, Gersten, Reynolds, Kallgren, & Ramirez, 1989). Students who experience both the presence and perception of a supportive social network tend to have higher self-esteem and are able to cope more effectively with difficult situations than do students without such support (Belle, 1989; Rohrlé & Sommer, 1994).

Conversely, the absence of or decrease in social support has been associated with a variety of difficulties in both adults and children, including depression and anxiety (Goethe & Levin, 1984; Wolchik, Beals, & Sandler, 1989), decreased self-esteem (Belle & Longfellow, 1983, 1984), a shift toward external locus of control (Belle & Longfellow, 1983, 1984), and conduct problems (Wolchik et al., 1989).

Social support, then, for students who have undergone stressful events, is especially important in that it may serve to shield them from some of the potentially harmful psychological and physical

influences of those stressful events. Given the extreme stresses associated with ABI, the benefits derived from the presence of an adequate support network are especially crucial to the student's adjustment to a major life change. In a study of young males with ABI (Willer, Allen, Durnan, & Ferry, 1990), the presence of social support was identified by the young men as one of five primary coping strategies and was described as "the most essential element in overcoming the limitations imposed by their disabilities" (p. 170).

In addition to the critical role that social support plays in a student's ability to cope with the stresses of ABI, friendships are of key importance even to the typical development of children without disabilities. That is, students learn from one another many aspects of social functioning as well as other life skills (Meyer & Putnam, 1987). This is especially true in school environments in which students are expected to work together and learn from one another in a variety of ways. Students with ABI, who tend to have fewer friends and impoverished social networks, are less able to benefit from these kinds of learning experiences. In this sense, the decrease in friendships experienced by a student with ABI can impede the child's overall development.

#### Effect on the Family

In addition to the adverse effects of a decrease in social networks on children with ABI, a loss of social support negatively affects families as well. Parents of children with ABI and other disabilities may experience demoralization stemming from their child's impairment or from a lack of supportive relationships outside of the home (Acorn, 1993; Seaver-Reid, 1986; Singer & Nixon, 1996; Turnbull & Turnbull, 1986).

The child's difficulties in maintaining friendships also add to the practical demands of caregiving experienced by families (Singer & Nixon, 1996). As former friends fade away, family members may increasingly try to fill the gap. These family members may become the child's only source of social support or may take on the responsibility of orchestrating the child's social life. In the words of one parent,

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 for Cub Scouts for three years . . . I've gotten him into baseball, basketball . . . I've been there to help with the coaches. (Singer & Nixon, 1996, p. 49)

Consequence of this increase in responsibility, both parents and siblings may find it difficult to get away in order to spend time with other people or to engage in other activities, thus adding to their fatigue and strain. Siblings of young males with ABI identified the increase in caregiving responsibilities as a key problem, and some even described a feeling of having become "assistant parents" (Willer et al., 1990, p. 171).

#### **Effect on the Child's School Experience**

A decrease in social networks also has a negative impact on the quality of the student's school experience (Vieth et al., 1996). On returning to school, the student may be rejected by peers while lacking effective strategies for coping with that rejection. One parent described her son's way of dealing with the teasing he received from peers as perpetually looking at the ground "so I don't have to see the expressions on other people's faces when they look at me" (Singer & Nixon, 1996, p. 41).

In addition to the emotional consequences of peer rejection in school, a lack of social support can increase the likelihood of the student's placement in a more restricted environment (Kozlowski, Phipps, & Hirtzing, 1983). That is, social isolation may lead to frustration, depression, and behavior problems that in turn contribute to the need for a more restrictive placement and a reduction in opportunities for social integration.

Furthermore, there is some evidence to suggest that the degree to which a student experiences (or lacks) adequate social support is directly related to educational outcomes because the presence of social support has been associated with students' higher academic achievement (Belle & Longfellow, 1984; Woods, 1972). Thus, a decrease in social support for a student with ABI may function to exacerbate the learning difficulties with which he or she must already contend.

#### **Effect on the Child's Community Involvement**

Being active and involved in a community is an essential element in anyone's quality of life, and the need for students with disabilities to be fully included in community activities and society as a whole has been frequently cited (e.g., Laski, 1991). The social isolation experienced by students with ABI often translates into a dramatic reduction in opportunities for participation in community leisure activities. Following the injury, students with ABI may often engage only in inactive, home-based activities such as watching television, reading, or playing with a computer (Lehr, 1990). These types of ac-

tivities consequently reduce the likelihood of their becoming or remaining genuinely involved members of the community—a loss both to the individual and to the community as a whole.

### **APPROACHES TO INCREASE AND ENHANCE SOCIAL RELATIONSHIPS BETWEEN CHILDREN WITH AND WITHOUT DISABILITIES**

Since the mid-1970s, a variety of approaches to increase or enhance social relationships and community involvement of people with disabilities have been developed (Cooper & McEvoy, 1996). Following is an overview of the major types of strategies that have been developed as well as the typical outcomes associated with each.

#### **Pairing Individuals with and without Disabilities**

One of the first organized and widely disseminated efforts to facilitate and enhance friendships between same-age peers with and without disabilities was developed by Voeltz and her colleagues (Voeltz, 1980, 1982). The Special Friends program recruited and matched elementary-age peers without disabilities to play with students with severe disabilities during recess, lunch, and activity times. School personnel encouraged and facilitated social interactions and play between the peers and were specifically instructed not to allow instruction or helping behaviors by the peer without disabilities. Positive attitudes toward students with disabilities and peer relationships among the students were found to increase as a result of participating in the project.

Other approaches have involved pairing students with disabilities with older students or adults without disabilities to increase friendship and involvement in community activities. The Fostering Friendships program (Cooley, 1989; Cooley, Singer, & Irvin, 1989), modeled loosely after the Big Brother/Big Sister program, paired university students with students with severe disabilities to take them out once a week for several hours to engage in community recreational activities. Participants indicated a high level of satisfaction with the program, the degree of participation in community activities increased for students with disabilities, and positive attitudes among the university students toward students with disabilities also increased.

#### **Person-Centered Planning**

Another type of approach to enhancing social inclusion entails involving the student and family more centrally in the educational or

every planning process. Examples of this strategy include the Circle of Friends approach (Forest & Lusthaus, 1989); Making Action Plans, or MAPs (Vandercook, York, & Forest, 1989) (formerly known as McGill Action Planning System [Lusthaus & Forest, 1987]); and Collaborative Problem Solving (Salisbury & Palombaro, 1992). Such approaches have resulted not only in enhanced friendship opportunities and support for individuals with disabilities but also in improved quality of service delivery to those individuals.

#### **Community Bridge-Building**

Another strategy employed has been to facilitate the involvement of individuals with disabilities in general community recreational activities or clubs. Termed Community Bridge-Building (Arsenault, 1990; Mount, Beeman, & Ducharme, 1988; O'Connell, 1988), this approach entails first identifying formal and informal opportunities available in the community for individuals to become acquainted with others with similar interests and then facilitating the inclusion of individuals with disabilities into these groups. A number of case studies have indicated that friendships between group members with and without disabilities developed as a result of this inclusion (Arsenault, 1990; Reidy, 1993; Strully & Strully, 1985).

#### **Inclusion in General Education Classrooms**

One key rationale underlying the growing trend toward including students with disabilities in the general education classroom is the need to increase opportunities for these students to interact socially with their peers without disabilities both in and out of class (Stainback & Stainback, 1990; Stainback, Stainback, & Jackson, 1992). Although it has been shown that some students with disabilities do increase their friendships by virtue of inclusion alone (Hall, 1994; Kaub, Schwartz, Gallucci, & Peck, 1994), others require more active promotion efforts on the part of teachers or others to have a meaningful effect on social interactions and relationships with peers without disabilities (e.g., Cole, 1986; Meyer et al., 1987; Voeltz & Brennan, 1984). The cooperative learning strategies employed in many general education classrooms in the 1990s have been identified as promising in their potential effect on students with disabilities because of their tendency to enhance the social relationships among all students (Gartner & Lipsky, 1987; Stainback & Stainback, 1992).

#### **Peer Tutoring**

Yet another approach to promoting social inclusion efforts is peer tutoring (Haring, 1991; Odom & Strain, 1986), which focuses on re-

cruiting and training students without disabilities to provide academic assistance to students with disabilities. Results of research on peer tutoring have shown an increase in positive social and academic skills by the students with disabilities as well as an increase in positive attitudes of the peer tutors toward individuals with disabilities (Gartner & Lipsky, 1990; Haring, 1991; Harper, Maheady, & Mallette, 1994). Peer tutoring has not been found, however, to have any effect on increasing friendships or involvement in social activities of students with disabilities. Moreover, the practice of placing students without disabilities in teaching or oversight roles vis-à-vis their peers with disabilities has been criticized because of the deleterious effect it can have on the formation of equal and reciprocal social relationships (Kishi & Meyer, 1994).

#### **THE BUILDING FRIENDSHIPS PROJECT: AN UP-CLOSE LOOK AT ONE APPROACH**

The Building Friendships approach was originally developed under a 3-year federally funded research grant from the U.S. Department of Education (Sowers, Glang, & Cooley, 1991). It focused on alleviating the social isolation that students with ABI experience by developing and enhancing school-based social networks. Research results from the study of this process (see Sowers, Glang, Voss, & Cooley, 1996) indicated that after being involved in the project, students, parents, and teachers reported that students with ABI increased their number of friends and also engaged more frequently in activities with their peers without disabilities. Parents and teachers also reported increases in their satisfaction with the students' social lives.

#### **The Process**

The Building Friendships process combines many of the features of MAPs (O'Brien, Forest, Snow, & Hasbury, 1989; Pearpoint, Forest, & Snow, 1992) and Circle of Friends (Perske, 1988; Snow, 1989) approaches. Like other person-centered planning strategies, this one strives to create an environment that encourages the student and family to direct as many aspects of the planning process as possible. Adaptations and modifications were made to the strategies previously developed in order to shorten the process, thus making it easier for people to participate as well as to place a greater emphasis on social network issues and follow-up activities.

The overarching goal of the Building Friendships process is to increase the quality of the student's social life through an ongoing, informal team process designed to bring together and mobilize important people in a student's life. The student, family, peers, and

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ils participate in a four-phase process led by a facilitator. Brief descriptions of the four phases, which consist of gathering information, recruiting team members, conducting an initial team meeting, and holding regular follow-up meetings, follow. Specific follow-up information is then provided.

**Phase I: Gather Information Through Interviews with the Student, Parents, School Staff, and Peers** The facilitator, typically an educator located at the school, first interviews the important people in the student's life to identify opportunities within school and community settings to develop increased social opportunities and to enhance current friendships. Information gathered during this first phase is used as a basis for the initial team meeting.

**Phase II: Recruit Family Members, School Staff, and Peers to Be Team Members** To develop broad-based support and to create a student- and peer-driven process, it is important to include a variety of team members at the initial team meeting. The student and family members play the primary role in determining which individuals to recruit as team members. In some cases this may include peers, extended family, and school staff whereas in other cases the initial meeting may involve a core group including the student, his or her parent(s), and several educators with whom the student has developed a close relationship. Team membership is fluid; new team members may be invited to participate at any time, and those team members who are unable to participate regularly may choose to attend meetings less frequently.

**Phase III: Conduct an Initial Team Meeting to Share Information and to Create Visions for the Future** The team identifies individualized social goals and specific strategies to meet these goals.

**Phase IV: Hold Regular Review Meetings** Every 2-3 weeks, team members meet to review progress, revise plans and strategies, and reevaluate team membership and responsibilities.

### The Team Meeting

The Building Friendships process, like MAPs, is a dynamic and fluid person-centered planning strategy aimed at increasing the students' and families' abilities to arrive at their own solutions to problems of social isolation. It emphasizes the importance of including peers as team members as early in the process as possible.

The MAPs process uses the following seven questions to help guide efforts of team members in increasing the successful inclusion of students with disabilities (Vandercook, York, & Forest, 1989):

1. What is the individual's history?
2. What is your dream for the individual?

3. What is your nightmare?
4. Who is the individual?
5. What are the individual's strengths, gifts, and abilities?
6. What are the individual's needs?
7. What would the individual's ideal school day look like?

Whereas MAPs addresses a full range of student-centered issues, the Building Friendships process focuses solely on social issues and is thus of shorter duration and more narrowly targeted. Following are the questions/steps used in the Building Friendships team meeting.

**Who Is [the Student]?** The facilitator asks team members to offer words and phrases to describe the positive qualities and attributes of the student. As participants share their thoughts, the facilitator records them with colorful markers on a large sheet of paper. This first question sets the tone for the rest of the meeting and for the entire Building Friendships program by focusing team members on the student's strengths and positive attributes. For some families, this can be an emotionally charged experience because it is the first time since their child's brain injury that they have heard professionals speak positively about their child.

**Hopes and Dreams** Next, team members state their hopes and dreams for the student within the social domain. After the student has the opportunity to state his or her own hopes and dreams, the other team members offer their hopes and dreams for the student. The facilitator checks with the student frequently to make sure that the hopes and dreams offered by other team members are acceptable and deletes those that the student does not want recorded. As long as the student accepts the hopes and dreams offered by others, every response is recorded and nothing is censored. This brainstorming process serves both to empower the student and expand the team's notion of what is possible. In some cases, the most important goals emerge from hopes and dreams that initially appear unrealistic.

**Circle of Friends** Based on the information previously gathered, the facilitator presents a prepared visual diagram representing the key people currently in the student's life. This diagram consists of four concentric circles with the student's name placed inside the innermost circle. Those closest to the student, trusted friends, acquaintances, and paid professionals are all listed on successive circles that extend outward from the student. The Circle of Friends diagram graphically depicts the nature of the student's social network (see Figure 1). In most cases, the diagram shows an abundance of acquaintances and paid professionals but few close friends. The goal of the Building Friendships process is to create opportunities for the student to make friends and expand his or her inner circle.

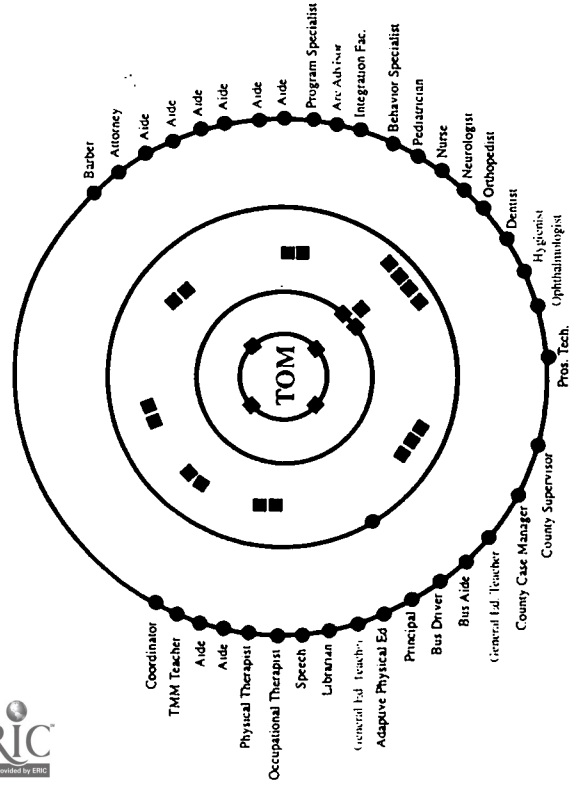


Figure 1. An example of a Circle of Friends diagram for Tom, a student. (■ = family; ● = nonfamily) (From Schlieben, S. J., Ray, M. T., & Green, F. P. [1997]. *Community recreation and people with disabilities: Strategies for inclusion* [2nd ed., p. 137]. Baltimore: Paul H. Brookes Publishing Co.; reprinted by permission.)

**Goals** Next, the team identifies several goals toward which to begin working. These goals, derived from the hopes and dreams created previously by the team, are fluid; the team may add or change goals in future meetings. The student has the final say in determining whether chosen goals are acceptable.

**Obstacles** The team next identifies obstacles to achieving the identified goals. Team members are asked to think of all the reasons it might be difficult for the student to reach the identified goals. Obstacles might involve financial constraints (e.g., Joey cannot afford to go to the video arcade), physical issues (e.g., Manuel's physical disabilities prevent him from playing soccer), or a school's approach to service delivery (e.g., Sarah's school has never had a student with disabilities participate fully in the second-grade class). This is the first opportunity during the meeting for team members to present "roadblocks" to meeting the goals set by the team.

**Strategies** After identifying possible obstacles, the team then brainstorm specific strategies for overcoming them. It is the facilitator's job to help the group move beyond accepted practices and develop creative approaches and solutions. Although some strategies might take a concerted effort to implement (e.g., setting up a

recess buddy system), others might be as simple as a schedule change to permit greater inclusion and opportunities with peers. The key to success at this stage is to encourage the team to adopt a "can do" attitude.

**Action Plan** The last step in the process is for the team to prioritize goals and strategies and then develop a specific plan that details how team members will achieve their goals. The action plan specifies which team member will take responsibility for which task and when each task will be accomplished.

### Menu of Strategies

Every student with ABI is unique. Therefore, the activities and strategies decided on will vary considerably from person to person. Following is a menu of strategies that might be included on a student's action plan, along with examples of each.

**Schedule Changes: Modifying a Student's Schedule to Increase Social Opportunities in Inclusive Settings** One of the key obstacles identified by Sarah's team was her isolation from peers without disabilities. Sarah's team changed her schedule so that she spent lunch, recess, and several hours each afternoon with the other third-grade students.

**Peer Education About ABI: Presenting Information About ABI to Peers with Specific Information About Their Peer's Experiences** In his middle school homeroom class, Richard and his mother presented a slide show about his rehabilitation from a severe brain injury several years earlier. The presentation included slides of Richard prior to his accident, during coma, and in various rehabilitation activities at the hospital. Richard's mother discussed the effects of the brain injury on Richard and their family. Richard and his mother then answered students' questions.

**Organized Recreational Activities: Linking the Student to Typical Recreational Activities in the Community** Tom's team explored community-based social and recreational opportunities to find ways for him to become more involved with peers outside of school. As a result, he became involved in a church youth group and began going to the YMCA after school several times a week to play basketball. Jessica joined a Camp Fire club, Ralph and another young man started working out in a gym three times a week, and Alison volunteered once a week at a preschool for low-income families.

**Friendship Clubs that Serve to Shift the Focus from One Targeted Individual to a Larger Group of Students** One instructional assistant began the Building Friendships process specifically for one of her students, Billy. As peer interest developed and grew, the focus

gra shifted away from an exclusive focus on Billy to a genuine concern for building a sense of community and belonging within the group as a whole. Soon Billy and his peers were meeting once a week to discuss concerns about friendships and were planning dances and other activities to engage in together.

**Buddy System for Getting to and from Class and at Lunch and Recess** Initially, it can be helpful to ask peers to volunteer to assist and spend time with students with ABI at lunch and recess. For example, Helen's team facilitator arranged for several students in other classes to eat lunch with Helen and to play with her at recess. These formalized arrangements were helpful in bringing students together and in getting them acquainted with one another. After several months, the formal buddy systems were dropped in favor of the more naturally occurring routines that had evolved over time.

**Cooperative Learning Activities: Structuring Classroom Activities so that Groups of Students Work Together Toward a Common Goal** Prior to his involvement in the Building Friendships process, Joey usually worked individually with the instructional assistant during most of math class. After the team meeting, Joey's math teacher created more opportunities for the students in Joey's class to work in cooperative groups.

**Social Events Outside of School: Planning a Group Activity in the Community** Ramon's team planned an after-school ice-skating party. Most of the students were able to attend, and the experience gave everyone an opportunity to get to know one another in a different way outside the academic setting. Ramon's joking, usually viewed as inappropriate during class time, was well received and reciprocated in this recreational context.

**Organizational Systems: Creating Compensatory Systems for Keeping Track of Important Information** Ted's team suggested that he use an audiotape recorder at school. This enabled him to record information for his classes (e.g., assignments, school schedule changes) and was a fun way for him to interact with other students as they taped messages for him. Each night he transferred the information into his memory log on his computer. Rachelle's team helped her create a book with pictures of her friends. Below each picture was the friend's name and telephone number. The idea was so popular among the group of friends that each one created his or her own photograph telephone book to aid in calling one another.

**Informal Weekly Lunch Get-Togethers at School** Jack and the peers involved in his team decided to eat lunch together once a week. Each week they met in a reserved classroom, and they often

took turns bringing special treats. After lunch the group played games and had organized discussions about topics of interest ranging from current events to the quality of cafeteria food.

**Classwide Disability Awareness/Community-Building Activities** As part of their involvement in the Building Friendships process, the facilitator for Billy's team coordinated a Brain Injury Awareness Week in the school gym. Each class spent their gym time rotating through various simulation exercises that were designed to provide students with the experience of having a number of different challenges associated with ABI. The facilitator for Michelle's team came to her health class several times and guided all of the students through some of the steps of the Building Friendships process. As each student talked about the importance of friends in his or her life, the focus of attention (and therefore, too, any pressure or embarrassment) was removed from Michelle.

**Attending Extracurricular School Functions** Through the efforts of their respective teams, Shawn obtained a student identification card and attended several school dances with his brother, Cody started taking photographs for the school newspaper, and Mandy became her school's softball team's statistician.

## CONCLUSION

Whether employing the Building Friendships process or any of the many other available strategies for increasing and enhancing friendship opportunities for students with ABI, there are several key features or guiding principles that are helpful to keep in mind:

1. **Every child is different; therefore, whatever approach is used must be tailored to meet that student's unique needs.** What works for one student may be inappropriate for another. Keeping the process creative, dynamic, and open to variation will further enhance its effectiveness. This flexibility is the essence of the Building Friendships process and others like it.
2. **Friendships involve reciprocity, so whenever possible, horizontal rather than vertical relationships should be emphasized.** Often, people tend to forget that the person with a disability has just as much to offer to a friendship as anyone else. Emphasizing this balance and stressing reciprocal relationships (as opposed to hierarchical or "helper-helpee" relationships) serves to maintain the dignity and contribute to the self-respect of the individual being singled out for assistance efforts.

3. **Though the commitment of at least one adult to serve in the facilitative role is vital, it is equally important to ensure that the process is as peer driven as possible.** On the one hand, an adult's ongoing commitment will help to ensure that necessary follow-through will occur. On the other hand, a process that is entirely adult or professional driven may lack credibility with or attraction for students. Therefore, it is crucial to strike a balance between adult and peer involvement. **Support from the school building administrator is critical.** Approaches that strive to facilitate more social opportunities within school settings need, at a minimum, to have the awareness of and tacit support from the school principal. Even more helpful is the principal's active support and encouragement because it provides team members with an increased sense of freedom to think creatively and try new things.
5. **Sensitivity to family issues is essential.** For some families, the child's loss of friends is a very difficult and sensitive issue. For example, one parent with whom the authors worked had initially been extremely reluctant to participate in the Building Friendships process. For the first time since her son's injury, she was confronted with the deep sadness she felt about her son's loss of friendships and loneliness. It took time for her to trust that this group of professionals and peers might actually be able to help her son reestablish important social connections. Awareness of and sensitivity to the issues faced by family members is a critical aspect of the Building Friendships process. For some families, simply managing day-to-day stresses by necessity outweighs the desire to help their children develop friendships. It is thus necessary to let families define the level and extent of participation comfortable for them. In some cases, this may mean accepting only minimal family involvement and shifting the focus to the school setting to increase a student's social network.
6. **Social isolation is different from emotional isolation, and alleviating the latter is the ultimate goal.** Weiss (1973) makes an important distinction between social isolation characterized by the absence of a peer network and emotional isolation that stems from a lack of deep, meaningful friendships. Many of the strategies discussed in this chapter are designed to address issues of social rather than emotional isolation. It is important to "keep one's eye on the ball" so to speak, however, by remembering the rationale and hope underlying the

effort to increase social networks and opportunities. Ultimately, the aim of such efforts is to increase the quality of a child's life by ensuring the presence in that life of genuinely supportive and caring friendships—something needed and deserved by everyone.

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**APPENDIX B: BUILDING FRIENDSHIPS MANUAL AND VIDEO**

# Building Social Networks for Children and Adolescents with Traumatic Brain Injury: A School-Based Intervention

**Objective:** Three boys, ages 8, 11, and 13, who experienced social isolation as a result of traumatic brain injury, were studied to investigate the effectiveness of a school-based, educator-mediated intervention aimed at increasing the social networks of students with traumatic brain injury. A four-phase problem-solving process was instituted in which a student-centered school team identified goals and strategies for increasing the student's social opportunities and then met frequently to review progress toward the goals. **Main Outcome Measures:** Frequency of students' social contacts with nondisabled peers, parent and educator social validation ratings, and participant observations. **Results:** The number of social contacts for each student increased over baseline levels and was maintained over the course of the study. Parents, teachers, and students were generally satisfied with the process and with the concomitant increases in students' degree of social integration. Anecdotal follow-up reports indicated that these results were not maintained over time. **Conclusions:** The study's findings raise important questions about the varying perspectives on the importance of social integration, the degree to which educators can serve as change agents in students' social experiences, and the type of follow-up support required to maintain increases in students' social interactions. **Key words:** *education, pediatrics, social support, traumatic brain injury*

**Ann Glang, PhD**  
Associate Research Professor  
Teaching Research  
Western Oregon State College\*

**Bonnie Todis, PhD**  
Associate Research Professor  
Teaching Research  
Western Oregon State College\*

**Eltzabeth Cooley, PhD**  
Senior Research Associate  
Director of Special Education Projects  
West Ed/Far West Laboratory  
San Francisco, California

**Jennifer Wells, PhD**  
Project Coordinator  
Oregon Center for Applied Science\*

**Judith Voss, MA**  
Research Associate  
Teaching Research  
Western Oregon State College\*

\* Eugene, Oregon

Address correspondence to A. Glang, Western Oregon State College, 99 West 10th, Suite 370, Eugene, OR 97401.

**P**ERHAPS the most difficult and long-lasting effects of traumatic brain injury (TBI) for children and young adults are the loss of friends, decreased involvement in social activities, and absence of social support.<sup>1,2</sup> Sustaining a TBI is a major life change, devastating not only for the youngster, but also for the family.<sup>3-7</sup> For many children, TBI threatens their developing sense of personal autonomy, independence, and emotional integrity.<sup>5,8-10</sup>

In the literature on adults with TBI, the two changes reported as having the most profound impact include a decreased frequency of social contacts and social alienation.<sup>11,12</sup> Looking at postinjury patterns of social support, Finset and colleagues<sup>13</sup> found that with

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passing time, survivors of TBI reported a significant decrease in the amount of time spent interacting with friends and a concurrent increase in the level of social dependency they had on immediate family members.

In a qualitative study of the effects of TBI on young adults, Willer et al<sup>2</sup> interviewed 12 families of young men (ages 14-25) with TBI. One of the most significant problems identified was difficulty gaining and maintaining friendships. Although social support was raised by all of the subjects in the sample as a primary difficulty, it was particularly problematic for those between the ages of 14 and 20. Even in cases of mild brain injury, social relationships are generally affected.<sup>14-16</sup>

#### FACTORS CONTRIBUTING TO SOCIAL ISOLATION

Students who survive TBI are often faced with profound cognitive, physical, and behavioral changes that result in unique learning needs for students.<sup>17-20</sup> In addition to the learning challenges, these students must also contend with related problems in the area of social functioning.<sup>21,22</sup>

Physical disabilities or fatigue associated with TBI may restrict a student's access to particular social activities that, by their nature, require physical activity. Behavioral changes stemming from the injury may contribute to the isolation as well. Students with TBI tend to display a range of maladaptive behaviors, including disinhibition, impulsiveness, decreased frustration tolerance, reduced anger control, poor judgment, decreased motivation, and insensitivity to others.<sup>5,23</sup> Peers and others in the student's environment may become alienated or confused by these changes in the student's behavior. Social inappropriateness, coupled with cognitive challenges, can significantly increase the likelihood that students with TBI will become and remain socially isolated.<sup>21</sup>

#### THE IMPORTANCE OF SOCIAL NETWORKS

Many studies have indicated that social support is important, even crucial to the psychological and physical well-being of adults,<sup>25,26</sup> with numerous studies reporting the buffering and even healing effects of social support on students experiencing severe life stressors.<sup>27-29</sup> Without adequate social support, both adults and children experience difficulties related to depression and anxiety,<sup>30-32</sup> decreased self-esteem, increased dependency,<sup>33</sup> and other psychiatric disorders.<sup>34,35</sup> A study by Oswald and colleagues demonstrated that "most children create large and manifold networks of relationships," and that the interactions within such relationships "promote social, cognitive, and sociocognitive competences."<sup>36(p184)</sup> A traumatic brain injury interrupts this process, often leaving a student unable to resume interactions and activities in the way that people close to him or her have come to expect. Hence the student's social network begins to dissolve, and the student becomes socially isolated.

Given the importance of social relationships to the healthy development of any child, and the critical buffering role they potentially play for students with TBI in particular, it is of utmost importance to develop, evaluate, and implement interventions that can prevent or alleviate social isolation of these students. Following is a description of one such intervention.

#### The Building Friendships process

The Building Friendships process<sup>37,38</sup> is a promising approach to improving the social networks of students with TBI. The process is a team-based problem-solving strategy derived from the growing work in the field of social support for individuals with disabilities.<sup>39-46</sup> Using a collaborative, student-centered approach, the model draws on several

intervention designs that have been used for building supports and networks for people with disabilities. The process brings together the student, his or her family, key school staff, and existing friends of the student to identify goals for increasing the student's social opportunities and strategies to help the student reach these goals. Progress in implementing the strategies is reviewed at subsequent bi-monthly meetings. Goals are revised, eliminated, and added as necessary. Because the process is fluid and dynamic,<sup>20</sup> it allows a school team to be creative in helping students develop their own solutions to the problems of social isolation. (See Sowers et al<sup>37</sup> for a complete description of the model.)

Our initial evaluation effort examined the effects of the Building Friendships process when it was implemented by outside consultants (Sowers et al).<sup>37</sup> In that study, consultants worked closely with school teams, but it was the consultant who coordinated all aspects of the process, from team recruitment to assignment follow-up. Results from this initial research indicated that following their involvement in the process, students with TBI, their parents, and teachers reported increases in both the number of friends the students had and the number of activities students with TBI engaged in with their nondisabled peers.

#### Purpose of study

The purpose of the current study was to evaluate the effects of the Building Friendships process on students' social networks when implemented without the assistance of outside consultants. Recent work in the field of special education suggests that interventions that take into consideration the school context and the variety of competing demands faced by school-based personnel are more likely to be adopted by schools.<sup>21,47,48</sup> Several features of the intervention—familiarity with the student and peers, in-depth knowledge of the school's policies and cul-

ture, and the need for close monitoring and communication among students, teachers, and parents—indicated that implementation by an on-site educator would be highly advantageous. It was therefore critical to show that the intervention could be delivered by educators rather than by outside consultants in order to establish its ecologic validity. Implementation by on-site staff has the added benefit of increasing the capacity of practitioners to meet the needs of students with disabilities in a highly individualized, systematic, and effective way.

To test the implementation using school-based personnel, the original Building Friendships process was adapted by developing training and support for facilitators and modifying procedures to include greater flexibility to accommodate different school cultures and context. In addition, because of the heterogeneity of both our research participants (students with a variety of types, extent, and sequelae of TBI) and the contexts in which the intervention was implemented, the research design incorporated multiple methodologies. This allowed an examination of the complexities of implementing an intervention such as the Building Friendships process.

## METHODS

### Subjects

Three pairs of facilitator and student participants for the study were recruited through a statewide notice to educators about a research project aimed at expanding the social networks of students with TBI. To be eligible for participation in the study, facilitators had to be working with a student who had sustained a TBI, was experiencing social isolation, and had parental consent to participate.

Applicants completed a brief application form that included information about their experience with students with TBI and a short essay describing why they were interested in being Friendship Facilitators. The in-

investigators then interviewed applicants to select the three most qualified Friendship Facilitators from the pool of applicants. Selection criteria included supervisor approval, the ability to work with the student 2 to 3 hours per week over a 4-month period, and being based in the student's school.

Parents of participating students signed informed consents listing the potential risks to confidentiality, safeguards against such risks, and potential benefits of their child's participation in the project. Students were told more informally about the project and its goals and activities, assured that they could stop participating at any time, and asked whether they wanted to participate.

#### **Subject 1: Manuel**

Manuel was injured in a bicycle-motor vehicle crash 4 years prior to his involvement in the study. In the crash he sustained a severe TBI, resulting in widespread diffuse damage. According to his family, Manuel was comatose for more than 2 months. Following a 4-month stay in acute care and rehabilitation hospitals, Manuel received outpatient therapy, which he continued to receive at the time of the study. He returned to school approximately 5 months following his crash.

Prior to his injury, Manuel was an excellent student. He performed above grade level academically; had many friends; and participated on the soccer, baseball, and basketball teams at his elementary school. Two years after his crash, Manuel's mother died of a brain tumor. His father subsequently remarried, and the family moved to a new home.

At the time of the study, Manuel was 11 years old. He lived at home with his father, stepmother, stepbrother, and sister. He had problems with gross and fine motor coordination and had significant expressive language deficits (slow, dysarthric speech). School staff reported that Manuel was easily frustrated and fatigued easily. On the Wechsler Intelligence Scale for Children-Revised

(WISC-III),<sup>49</sup> Manuel received a full-scale IQ score of 93. A fifth grader in his local grade school, Manuel performed at grade level academically. He had a full-time assistant to help with writing and with getting to and from class. While the school staff reported some inappropriate behaviors (interrupting others' conversations, making faces, and laughing during class), the primary problem they identified was his social isolation. Most of the time Manuel ate lunch alone at his desk, and at recess and other unstructured times, he was either with his assistant or with one of his therapists. Manuel was satisfied with his friendship network. He felt that he was well treated by his peers and said that he felt that most students were his friends. Manuel's father felt that Manuel had had fewer friends since his crash, but that this was not a big problem. He attributed Manuel's lack of friends to their family's recent move.

Manuel's instructional assistant, Linda, who nominated him for participation in the project, had a different perspective on his social situation, however. She felt that any interaction Manuel had with peers occurred because she promoted it by inviting Manuel's classmates to join her and Manuel in games on the playground or to work with them on projects in the classroom. Once the peers had joined them, she worked hard to facilitate interactions between the peers and Manuel. Linda was concerned about Manuel's dependence on her for social opportunities, especially because Manuel and his classmates would be moving to middle school the following year, where the social "rules" and norms would be much different and Manuel would have to be more independent and assertive in order to be part of any social network.

#### **Subject 2: John**

John sustained a TBI as a 3-year-old in a motor vehicle crash. He experienced a mild brain injury, had no loss of consciousness, and was not hospitalized. John's family re-

ported that he had been developing normally prior to the crash. After his injury, he stopped talking for approximately 1 year and became aggressive and difficult to manage. When John started kindergarten, school staff identified him as needing special education services because of his behavior problems and severe language delay (articulation problem and dysphasia). On psychological testing completed 3 years after the crash, John scored in the average intellectual range, with much lower scores on verbal subtests.

John was an 8-year-old second grader when he participated in this study. He lived in a small town in his grandmother's home with his mother, stepfather, brother, and five members of his extended family. He attended school only part-time because of his disruptive behavior, which primarily involved physical aggression toward adults and peers when he was frustrated or wanted attention. At school he had a full-time instructional aide who helped manage his behavior and assisted with schoolwork. When John became violent, his assistant physically restrained him so that he would not injure himself or others in the class. John's mother and teacher reported that he had no friends and was very isolated socially. Other children, at school and in his neighborhood, were afraid of his outbursts and kept their distance. At home, John played with his cousins or by himself. He reported that he had several friends at school and was happy there, but had no one to play with at home. Thus, although John's brain injury was a mild one, the social, behavioral, and academic challenges he faced were similar to those experienced by the other two subjects whose injuries were more severe, and these challenges prevented him from experiencing success in the school setting.

### *Subject 3: Theo*

Theo was a 13-year-old boy who sustained a closed head injury when he was struck by a

motor vehicle 6 years prior to participating in the current study. The crash resulted in a basilar skull fracture with subdural hematoma and intraparenchymal hemorrhage. Theo was comatose for approximately 3 weeks. After a 6-week stay in an acute care hospital, Theo received outpatient rehabilitation daily for 3 months. He returned to school approximately 5 months after the injury.

Theo had been a very good student before his crash. He had many friends and played on several sports teams. After his injury, he experienced severe problems with attention, memory, and visual-motor abilities. Three years after the crash, Theo's Full-Scale WISC-III IQ score was 77 (performance, 78; verbal, 80).

At the time of his participation in the study, Theo was in the seventh grade. His parents had divorced 2 years prior, and he lived in a rural community with his mother and younger brother. Although several years below his peers academically, he attended regular classes at the local middle school, with assistance from special education staff in the resource room and for part of each class period in the regular classrooms. Unfortunately, the accommodations made for Theo were inadequate; every term Theo and his mother were upset when he received failing test scores in classes in which he thought he was performing well.

For Theo's mother, his lack of friends was a dramatic change from before his injury. He reported to her that other students at his school made fun of him and called him "retard" and other derogatory names because of his slow response rate and speech. She expressed her concern to the special education staff, who took a closer look at Theo's interactions with peers. They noted that Theo had one friend, and that when this friend was absent or in a different class, Theo's social interactions dropped to zero. Unfortunately, when Theo was with his friend Dave, they



were both noncompliant, noisy, off-task, and insubordinate in the classroom and sometimes got into confrontations with other students in the halls and lunchroom. Observations revealed that Dave often set Theo up to do things for which he was likely to get in trouble.

### Facilitators

The three Friendship Facilitators were special educators based in the schools the students attended. The facilitator who worked with Manuel was an instructional assistant who was assigned to Manuel to provide the accommodations he needed because of his brain injury. Theo's facilitator was also an instructional assistant, but her role was to provide general support to many students who received special education services. John's facilitator was his special education teacher. Each of the facilitators was paid a stipend of \$500 for their involvement in the study. In return, facilitators agreed to spend several hours a week for a period of 3 to 4 months coordinating the Building Friendships process. This included keeping detailed logs of all activities associated with the project, following up with team members to make sure assignments were completed, collaborating with the investigators on refinement of the process, and participating in weekly telephone interviews.

### Procedures

#### *Facilitator training*

Friendship Facilitators attended a day-long workshop on the Building Friendships process coordinated by the investigators. Following a presentation about social issues specific to students with TBI, the facilitators learned the steps involved in using the Building Friendships process, as well as a variety of specific strategies for increasing a student's social involvement. Training formats in-

cluded didactic presentation, videotape, and role-play. Each of the facilitators had an opportunity to practice using the skills presented and received feedback from the presenters. Facilitators also learned specific data-keeping procedures to document group activities.

The investigators maintained weekly telephone contact with each of the facilitators throughout the study. Topics of discussion included how to deal with behavioral issues, helping the students' families problem-solve conflicts that arose between the students and their friends, and how to diminish adult intervention and encourage the peer group to plan activities independently.

#### *Implementation of Building Friendships process*

The primary goal of the Building Friendships process is to increase the quality of the student's social life through an ongoing, informal team process designed to bring together and mobilize key people in a student's life. The student, family, peers, and professionals participate in a four-phase process led by a facilitator (see box, "Four Phases of the Building Friendships Process").

Although each facilitator followed the four-phase process, the specific nature of each implementation varied because it was tailored to each student, team, and school context. In each case, the facilitator met briefly with the student, his parents, and at least one key educator to determine the nature of the student's current friendship network. Next the facilitator recruited between four and eight team members. Over the course of the study, for each student, the core friendship team consisted of the student, parent, facilitator, and at least one peer, with additional members (eg, coach, additional peers, siblings) attending when possible. At the initial team meeting, the team followed a predetermined agenda (see box, "Agenda for Initial

### Four Phases of the Building Friendships Process

*Phase I.* Gather information through interviews with the student, parents, school staff, and peers. The facilitator interviews the key people in the student's life to identify opportunities within school and community settings to develop increased social opportunities and to enhance current friendships.

*Phase II.* Recruit family members, school staff, and peers to be team members. The facilitator works with the student and family members to recruit team members. Team membership is fluid; new team members may be invited to participate at any time, and those team members who are unable to participate regularly may choose to attend meetings less frequently.

*Phase III.* Conduct an initial team meeting to share information and to create visions for the future. The team identifies individualized social goals and specific strategies to meet these goals. The student has "veto power" over any goals or strategies selected.

*Phase IV.* Hold regular review meetings: Every 2-3 weeks, team members meet to review progress, to revise goals and strategies, and to reevaluate team membership and responsibilities.

Building Friendships Team Meeting") to develop a specific action plan that addressed the student's goals. Ongoing team meetings with the core team members occurred every 2 to 3 weeks over a 3- to 4-month period (a total of nine meetings for Manuel, three for John, and six for Theo).

### Design

A multiple baseline, across subjects design was used to evaluate the impact of the Building Friendships intervention on the students' social integration. The intervention was introduced sequentially by each facilitator once baseline measures stabilized.

### Experimental conditions

There were two experimental conditions: baseline and implementation of the Building Friendships intervention. During the baseline condition, there were no changes in the students' regular programs. Each student's parent and friendship facilitator were called on the telephone weekly to collect probe data regarding the number and types of social interaction in which the student had engaged at school the previous week.

During the intervention phase, the facilitators implemented the four-phase Building Friendships process (see the box). Variations in the process involved the types of strategies implemented to facilitate increased social interaction, the nature of team meetings, and the degree to which the facilitator involved

### Agenda for Initial Building Friendships Team Meeting

1. Who is [the student]?
2. What are the student's hopes and dreams in the area of friendships?
3. Who is a part of the student's current Circle of Friends?
4. Prioritize several goals to begin working toward
5. Identify obstacles to achieving the identified goals
6. Brainstorm strategies for overcoming the obstacles
7. Develop a specific action plan to help the student achieve their goals

peers in the process. For example, Manuel's facilitator, Linda, organized a weekly lunch meeting with a large group of peers. Each week they planned an activity, such as playing in the gym, eating pizza, or watching movies. In addition, Linda and the school counselor invited a group of peers from the middle school to have lunch and learn about Manuel's experiences from Manuel and his father. John's facilitator tried to take the focus off John by including many peers in a Friendship Group that hosted several lunch meetings and a school dance. Theo's facilitator involved Theo's team, including his family, in problem-solving activities designed to help his friend David better understand Theo's behavior. The team also worked to involve Theo and David in community activities.

#### **Dependent measures**

Recent research in special education has increasingly incorporated both quantitative and qualitative approaches.<sup>50,51</sup> Several features of this study invited the use of multiple research methodologies. The study focused on a new intervention in an area in which little previous research had been done: promoting social interactions for students with TBI. Because the field and intervention are new and complex, it would be difficult to predict all of the potential outcomes and design instruments to measure them quantitatively. Qualitative methodology is well suited to such interventions, in which the research variables are not yet known and which may produce unanticipated but interesting outcomes.<sup>52,53</sup> Combining methodologies provides a holistic view of the intervention and its effects on participants that is helpful in understanding not only whether the intervention works, but also why it works or why not.

#### **Social contacts**

This measure was used to determine the degree to which students were engaged in

social interaction without any direction or assistance from an adult. A "social contact" was defined as a student with TBI interacting with a peer without disabilities<sup>54</sup> without adult intervention for 10 minutes or more outside of the classroom setting (eg, before and after school, at recess breaks, or at lunch). Examples of social contacts include having lunch with peers from the fourth grade classroom, interacting with a group of peers during midmorning break, and attending a school dance with a peer. Examples of interaction not counted as social contacts are participating in a cooperative learning activity in the classroom, wandering around during break without interaction, or playing ball with the instructional assistant and peers. Because descriptions of the activities, as well as the number, were recorded, we were able to assess qualitative factors related to the social contacts reported. Facilitators kept track of each social contact on a classroom log. A research assistant who was familiar with the facilitators and school settings collected data by interviewing each facilitator weekly and recording the number of social contacts they reported for the week. The research assistant followed a standard protocol during the interview to maintain the definition of social contact.

#### **Social validation**

To examine the general impact of the process on the student's social inclusion, facilitators were asked during the weekly interview to rate the degree to which the student was a part of "regular school life" using a Likert-type scale (1 = not at all included, 4 = very included). Parents and facilitators were then asked to rate their satisfaction with the degree to which the student was included. In addition, facilitators were asked how satisfied they thought the student was with his or her social inclusion for that week. These repeated measures of social validity were used to gain an understanding of the degree to which par-

ticipants' satisfaction varied over the course of the study. As part of the weekly interviews, the interviewer recorded verbatim statements from facilitators and parents regarding satisfaction with the intervention and with the student's social activities and overall social inclusion for that week.

Our initial research design also included social validation data from students. However, during our initial weekly telephone calls with each of the students it became clear that the students' communication difficulties and resistance would prevent us from getting accurate information. Manuel refused to talk with the research assistant. John's responses, or lack thereof, indicated that he did not understand the questions. Only Theo provided reliable responses to the social validation inquiries. Theo, however, was difficult to reach by telephone, and these data were recorded only sporadically. Because social validation data from students were incomplete, they are not included here.

#### *Participant observations*

Field researchers conducted participant observations with each of the three students. The 3-hour participant observations took place at school and included samples of all parts of the school day, including unsupervised activities between classes, lunchroom interactions, playground social interaction, and activities organized as part of the Building Friendships intervention. The field researchers prepared detailed field notes following each observation, recording details of the context of each observation, verbatim reports of key conversations, and descriptions of interactions. The field notes also contained the researchers' impressions of student, peer, and staff affect; changes observed between one observation and the next; and patterns or themes noted across observations.

Field notes and comments from the interviews were coded by topic area. These topi-

cal codes were combined into more general themes, including membership, peer perspective, modifications (to the intervention), and satisfaction (of participants). Themes were analyzed within each case to track the impact of intervention activities, school- or home-based events, and other factors on the satisfaction ratings of each of the participants in each case. Themes were also analyzed across cases to compare how different contexts, student profiles, facilitators, social issues, and intervention implementations produced similar or different effects for participants.

#### *Reliability of measures*

Several procedures were employed to increase the reliability of the data collected during weekly telephone contacts with facilitators. First, the research assistant used a standard interview protocol that included the definition of "social contact." This ensured that the definition of social contact was maintained throughout the duration of the study. Second, the research assistant and investigator met weekly to review the data for accuracy and to clarify any questions that arose. Finally, 30% of the telephone logs were reviewed for accuracy by the investigator. The investigator checked the detailed notes compiled by the research assistant to ensure that participants' comments and numeric responses were coded accurately. No significant discrepancies were found during this review.

#### RESULTS

Figure 1 shows the number of weekly social contacts for each student during each of these phases. Baseline frequencies were generally quite low for all three students (mean, 2.14; range, 0-8). During unstructured, nonclassroom time, the students were generally by themselves or with adults. The one

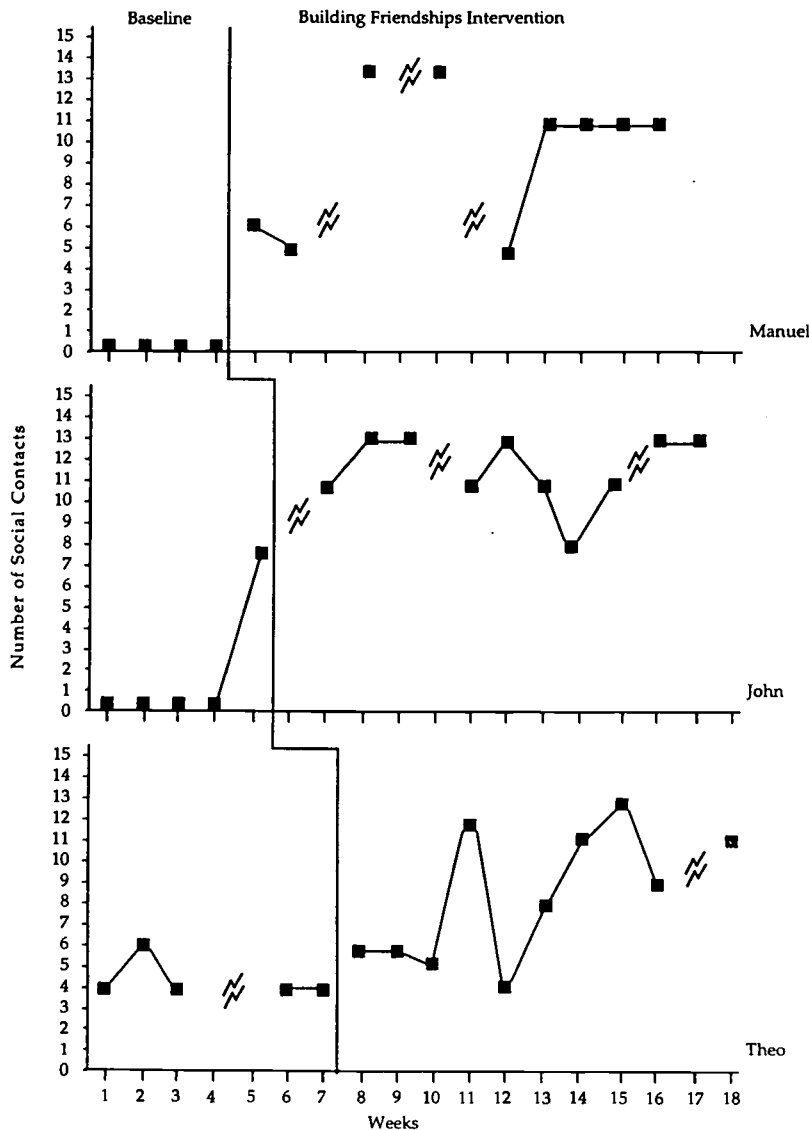


Fig 1. Number of social contacts per week engaged in by each student.

exception was on the final week of baseline for John, when his facilitator reported eight social contacts for the week, most likely due to her desire to get started with implementing strategies after talking with the investigators about the study and being involved in baseline data collection.

Following the implementation of the Building Friendships process, the number of social contacts increased and were maintained at higher levels for each student. Analysis of variance was used to determine if there was a phase effect. Using the appropriate within-subject error term for evaluating the test sta-

tistic  $F$ , a significant phase effect was obtained ( $F_{3,38} = 33.12$ ;  $P < .01$ ). During the intervention phase, the average number of weekly social contacts was 9.9, compared to an average of 2.1 during baseline. As a result of their participation in the intervention, students spent more time with their peers on the playground, at lunch, and before and after school. Examples of activities include playing with peers at recess, eating lunch with friends from the general education classroom, and attending a school dance with a friend.

### Social validation

One of the primary goals of the intervention was to increase the degree to which students were socially integrated at school. Facilitators were asked weekly to rate the degree to which students were socially included using a Likert-type scale (1 = not at all included, 4 = very included). During baseline, facilitators perceived students to be somewhat included (mean, 2.5; range, 1-4), whereas during the intervention phase, facilitators rated their students as very included (mean, 3.6; range, 3-4).

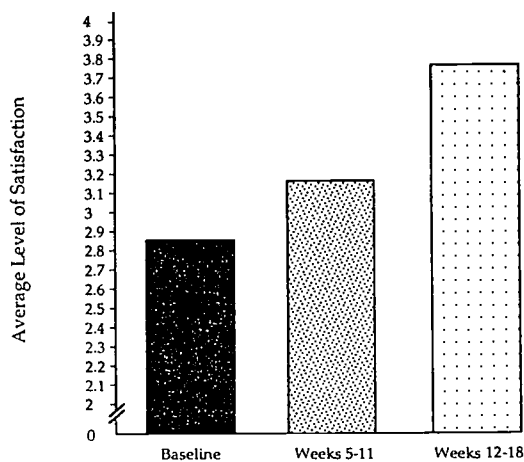


Fig 2. Average rating of parent satisfaction with student's level of social inclusion (2 = somewhat satisfied; 4 = very satisfied).

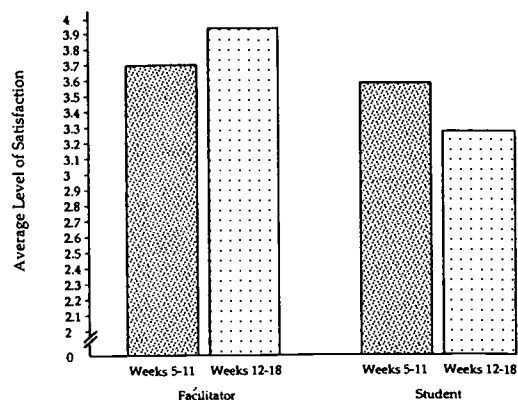


Fig 3. Mean facilitator satisfaction and facilitator perception of student satisfaction with student's social inclusion during implementation of Building Friendships intervention.

Figure 2 presents the mean satisfaction ratings for parents across baseline and intervention (the intervention period is divided into two phases, representing the first and second halves of the intervention period). As the intervention progressed, parents became more satisfied with their children's social integration.

Facilitator and student satisfaction ratings are presented in Figure 3. Facilitators were asked to rate how satisfied they were with their student's social inclusion, and how satisfied they felt their students were. As depicted in the figure, facilitators became more satisfied as they implemented the Building Friendships process, while they rated their students' satisfaction as decreasing over the course of the project.

### Qualitative data

Comments recorded as part of the collection of rating data and interviews with teachers provided anecdotal information on other changes that facilitators and parents felt might have been related to the intervention. Both John's facilitator and his mother reported improved behavior at home and at

school, although this could not be attributed solely to the Building Friendships Project, since his facilitator had implemented an anger management program at the same time. However, both at home and at school, John was reported to be happier, more cooperative, and able to engage in longer interactions with a wider variety of peers:

- He's doing all of his homework. He does what he's told. It's like I have a different kid! (Parent report, week 7)
- John has had no bad [behavior] days since we started doing [the Building Friendships project]. (Teacher report, week 9)
- He's able to ask kids to play more, and he doesn't play rough anymore. Kids tell me how much fun he is to be around. (Teacher report, week 11)
- Kids in the neighborhood are coming over to play with him. When he does get mad, he goes off alone and cools down. (Parent report, week 12)
- He's getting to be a polite little boy. A neighbor asked me, "What happened to John? He's changed!" (Parent report, week 16)

Comments made during the interviews also clarified the inconsistencies between facilitator and student satisfaction with the process. For example, commenting on the discrepancy between her satisfaction of 4 (the highest possible) and her opinion that Theo's satisfaction would be rated 2, his facilitator said, "I can see that he is much more included and has more friends. He would like to be *more* included. I can see there is more to be done. I wish I had more time to devote to this."

There was also anecdotal information that the quality of peer interactions improved as a function of changes in attitudes of peers. Theo's facilitator reported that the quality of Theo's interactions with Dave improved as Dave got a better understanding of the effects of TBI and as Theo became more assertive

about telling Dave to stop teasing him. For example, during one interview, Theo's facilitator reported that "Dave is treating him differently. He is more patient with him. He doesn't make fun of him." The facilitator also noted that Theo was more likely to initiate interactions with peers other than Dave, even students he didn't know, as the intervention progressed. He participated in lunch hour basketball games and invited new peers to his Building Friendships meetings.

## DISCUSSION

The purpose of this study was to assess the impact of the Building Friendships process on the social integration of three students with TBI who were experiencing social isolation. A secondary aim of the study was to determine the extent to which such an intervention could make a difference in students' social integration when implemented by school personnel within the school setting, as opposed to being implemented by outside consultants.

Results from this preliminary investigation were mixed. They indicated that the Building Friendships process—a school-based, educator-mediated intervention—was effective in increasing students' social interactions at school, for at least two of the three students. For Manuel and Theo, the effects were clear: Immediately following the implementation of the process, these students began interacting more frequently and spontaneously with their peers. For John, however, there was considerable increase in the frequency of social contacts during the baseline phase. This increase was apparently due to the confounding influence of John's facilitator implementing social-behavioral strategies during this (baseline) phase of the study. Nevertheless, both John's mother and his facilitator attributed his increased cooperation and interest in school to the Building Friendships interven-

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tion. The fact remains, however, that a functional relationship between independent and dependent variables was demonstrated for only two of the three students.

It may be argued that the effects demonstrated in this study can be attributed to factors other than the Building Friendships process. For example, students may have become more socially integrated because of changes in their parents' attitudes toward friendships, the attention they received from their facilitator or team, or the strategies the team employed. In other words, the positive effects demonstrated might be attributable to one component of the process rather than the entire package. Further research is needed to document more fully the effectiveness of the components of the Building Friendships process.

With respect to the social validation measures, both parents and educators reported feeling positive about their impact of the process on the student's social life at school. However, the facilitators' ratings of student satisfaction actually decreased slightly over the course of intervention, a finding that warrants further investigation. One possible explanation for this finding that was supported by the qualitative data was that prior to intervention, the students seemed to lack an awareness of the degree to which they lacked social interactions with their nondisabled peers. For example, one student (Manuel) questioned his facilitator early in the intervention about why he needed to have more friends when he already had one at recess (another special education student).

Perhaps due to the rather great extent to which these students' parents and teachers facilitated their social experiences within the special education setting, they seemingly did not notice the lack of interaction with their nondisabled peers. According to the comments made by parents and facilitators, the intervention served in part to draw attention

to this lack for the students' themselves, and this focus on what was not occurring perhaps contributed to a decrease in the students' own satisfaction levels. Moreover, even when the numbers of social contacts objectively increased, the students' focus seemed to remain on what was still missing in comparison to their newly raised expectations.

Finally, and perhaps most seriously, anecdotal follow-up data indicated that the increases in students' social contacts were not maintained over time once the facilitators' involvement had ceased and the students had moved on to the next grade level. This suggests that while peers of the students with TBI were willing to take advantage of opportunities provided them to interact with the target student, the peers' attitudes toward the student did not change to the extent that they were motivated to create their own opportunities for interaction. The fragility of these outcomes raises further questions about the nature of the changes produced by the intervention and the extent of follow-up support required for such interventions in the future.

With regard to the study's secondary aim, that of assessing the degree to which an intervention of this sort can be effectively implemented by school personnel within the school setting, two related issues emerged. First, there is differential agreement among families over the extent to which social issues ought to be a focus within the school setting. Many families tend to regard academic matters as the essential province of the school and thus regard socialization issues as more peripheral or extraneous. Beliefs about what constitutes adequate social support also contribute to a family's view of this issue. Manuel's father, for example, expressed his belief during the baseline phase that Manuel's interactions with siblings and extended family members were and ought to be sufficient for him.

School personnel also have differing levels



of interest in and/or availability for enhancing students' social opportunities. This issue was especially visible at the middle and secondary school levels. Typically, middle and high school teachers see hundreds of students throughout the school day and simply may not notice students' social isolation if it is not directly associated with behavioral problems. School-based social "interventions" most typically involve separating students who, when together, tend to cause disruptions. Rarely, though, do teachers intervene to assist socially isolated students find friends to have lunch with or walk to class with, so the extent to which teachers, especially those at the secondary level, would seek out and implement an intervention of this type remains a question.

### CONCLUSION

Taken together, the findings from this study perhaps raise more questions than they answer. However, the study contributes usefully in a number of ways to efforts in this area. First, there has been a notable lack of empirically validated strategies that educators can use to help students deal with the social challenges associated with TBI. Feeney and Ylvisaker<sup>21</sup> list three critical features necessary to effective school-based interventions:

1. The intervention must be delivered in natural settings, using "everyday" people as the primary agents of change.
2. Individuals must be engaged in planning their own intervention and making choices whenever possible.
3. The intervention must be delivered in

the context of and designed to effect change in daily routines.

The Building Friendships intervention evaluated by this study incorporated each of these components, and the findings add to our knowledge about what specifically can be done to increase students' social contacts.

Perhaps equally valuable are the unanswered questions and key issues identified by this study, such as the following:

- How can social network enhancement interventions serve to raise students' expectations about what is possible for them socially while at the same time fostering a realistic attitude that prevents "setting them up" for later frustration and disappointment?
- What kind of and how much follow-up support is required to maintain increases in students' social interactions gained through intervention? Are there ways to gradually diminish team support so that the process is self-sustaining?
- To what extent is it feasible to employ teachers as change agents in students' social experiences? What kinds of additional support or training would be required to systematically support this emerging facet of a teacher's already comprehensive role?

The answers to these and other complex questions related to the social integration of students with TBI await additional research. Although design and implementation issues related to these questions will be challenging, the importance of social support in the lives of children and adolescents with TBI merits the effort required to find the answers.

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83

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17

## Enhancing Friendships and Leisure Involvement of Students with Traumatic Brain Injuries and Other Disabilities

*Jo-Ann Sowers, Ann E. Glang,  
Judith Voss, and Elizabeth Cooley*

Since the 1980s, we have witnessed a growing belief that individuals with disabilities, including those with severe disabilities, should be fully included in school, work, and their communities (Nisbet, 1992; Taylor, Biklen, & Knoll, 1987). This belief has been accompanied by ongoing shifts in best practices and models. In areas of schooling, recommended practices have evolved from segregated schools, to self-contained classrooms in general schools, to inclusion in general classrooms (Jorgensen, 1992; Villa, Thousand, Stainback, & Stainback, 1992). In 1985, the only employment opportunities for most individuals with severe disabilities were in sheltered programs. The supported employment and job coach models have demonstrated that these individuals can work in typical businesses (Wehman & Moon, 1988; West, Revell, & Wehman, 1992). Through the job coach approach, supported employment staff have taken the primary

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responsibility for training new employees with disabilities. It has begun to appear that many businesses and co-workers are willing and able to provide much of the initial training when provided with proactive consultation from supported employment staff and that this approach may enhance both the long-term job retention and social integration of supported employees (Hagner & Dileo, 1993; Nisbet & Hagner, 1988; Sowers, 1995). Recent years have seen the widespread understanding that large institutions are not acceptable (although some continue to exist). Recommended practices for individuals with disabilities have moved from large group homes to smaller group living arrangements to the opportunity to rent and own homes (Klein, 1992).

Inclusion in typical leisure and social activities, including the development of acquaintances and friendships with individuals without disabilities, has been another important arena for evolving beliefs and practices since the 1980s. Earlier, "special" recreation activities were the widely accepted best practice approach to fulfilling the social and recreational needs of individuals with disabilities. It was assumed that these individuals' social and friendship network should and would primarily comprise other individuals with disabilities. Beliefs have begun to shift to an understanding that these individuals should have the opportunity to participate in regular and typical social and leisure activities and to develop acquaintances and friendships with individuals who do not experience disabilities (Grenot-Scheyer, 1994; O'Brien & O'Brien, 1993; Schleien, Meyer, Heyne, & Brandt, 1995; Staub, Schwartz, Gallucci, & Peck, 1994; Voeltz, Wuerch, & Wilcox, 1982).

In this chapter we provide an overview of the literature related to the implications of friendship and leisure participation on the self-determination of children and youth. We also provide a brief review of the major approaches that have attempted to enhance the friendships and leisure participation of individuals who experience disabilities. Two projects conducted by the authors are described in detail. The first is a comprehensive approach to enhancing friendships and leisure participation conducted with students who have experienced traumatic brain injuries. The second is a community bridge-building project aimed at students with severe disabilities transitioning from school.

### **FRIENDSHIP AND LEISURE: IMPLICATIONS FOR SELF-DETERMINATION**

There is substantial evidence of the impact and importance of social relationships and leisure participation on the self-determination and self-esteem of children and youth without disabilities. Children and youth who perceive that they have supportive friends have higher self-esteem than those individuals who do not perceive the presence of supportive friendship networks in their lives (Mannarino, 1976; McGuire & Weisz, 1982; Townsend, McCracken, & Wilton, 1988). There is also the understanding of the impact that peer interactions and culture have on the development of autonomy and self-determination. For example, it has been found that once children enter child care and educational settings they very quickly develop a strong identity with their peers and engage with these peers in challenging teachers and adult caregivers (Davies, 1982; Rubin, 1980). It has also been shown that children attempt to gain control over fears, confusion, and curiosity evoked by the adult world through their participation in numerous play routines, rituals, and games (Garvey, 1984; Goodwin, 1985). The literature on typical adolescent development supports the important role that peers play for

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youth in the development of self-determination. As children reach adolescence, they report an increasing reliance on peers and friends for advice, understanding, and acceptance and as the means through which they can reflect and define themselves, their values, and their goals (Corsaro & Eder, 1990; Griffin, 1985; Wulff, 1988; Youniss & Smoller, 1985).

The critical role that participation in leisure activities has in the development of self-determination has been widely discussed in the child and adolescent development literature. For example, many have argued that individuals learn to direct their lives through setting goals, attempting to achieve them, and evaluating their progress toward reaching them (Lerner & Busch-Rossnagel, 1981; Sibereisen, Eyferth, & Rudinger, 1986). Oerther (1986) suggests that school and work settings provide relatively limited opportunities for these experiences because of the structure and control imposed by others on the activities engaged in by students and employees. In contrast, Oerther believes, free-time activities give individuals the best opportunity for self-determination experimentation. Dattilo (1994, 1995) has also suggested that leisure participation provides an excellent context in which to teach choice. He had developed and tested a systematic instruction approach for teaching leisure making choices.

A number of studies have looked at the extent to which adolescents choose to spend their free time in different types of activities. The most frequent free-time activity of high school students was socializing with friends (Csikszentmihalyi & Larson, 1984). Research suggests that membership in an organization is also common for many teenagers. The positive impact of formal organizational activities on participants' self-determination, both short-term and into adulthood, has been validated by a number of research studies (Hanks & Eckland, 1978; Hedin & Conrad, 1981; Spady, 1970).

## REVIEW OF RELATED RESEARCH

Since the mid-1970s, a wide variety of approaches have evolved to enhance the friendship and leisure participation of individuals with disabilities. In this section, we review the major types of approaches that have been made and summarize the outcomes that have been achieved.

### Pairing Individuals with and without Disabilities

Voeltz and her colleagues conducted one of the first organized and widely disseminated efforts to facilitate and enhance social interactions and friendship between elementary-age peers with and without disabilities (Voeltz, 1980, 1982; Voeltz, Kishi, Brown, & Kube, 1980). The "Special Friends" program recruited and matched peers without disabilities to play with students with severe disabilities during recess, lunch, and activity times. School personnel encouraged and facilitated social interactions and play between the peers and were specifically instructed not to allow instruction or helping behaviors by the peer without disabilities. Positive attitudes toward students with disabilities and peer relationships among the students were found to increase as a result of participation in the project.

### Peer Tutoring

The second major line of social integration and interaction efforts has focused on peer tutoring (Haring, 1991; Odom & Strain, 1986). The results of research on peer tutoring have shown an increase in positive social and academic skills by the students with dis-

abilities and an increase in positive attitudes of the peer tutors toward individuals with disabilities (Gartner & Lipsky, 1990; Haring, 1991). No research has illustrated an actual impact of peer tutoring on friendship or social activity involvement among peers with and without disabilities. The potential deleterious effect on the formation of reciprocal and equal social relationships of placing students without disabilities in a teaching and oversight role has been voiced in the literature (Kishi & Meyer, 1994).

### **Peer Involvement in Planning**

A third social integration enhancement model identified by Kishi and Meyer (1994) is the involvement of peers in the educational planning of students with disabilities. Examples of these approaches are the circle of friends (Forest & Lusthaus, 1989), the McGill Action Planning System (MAPS) (Vandercook, York, & Forest, 1989), and the collaborative problem-solving approach (Salisbury & Palombaro, 1992).

### **Community Bridge-Building**

Another important approach has been the facilitation of involvement of individuals with disabilities in regular community recreational activities. This approach has frequently been termed community bridge-building (Arsensault, 1990; Mount, Beeman, & Ducharme, 1988; O'Connell, 1988). Community bridge-building involves identifying formal and informal organizations and activities that offer opportunities for individuals to get to know each other and to develop relationships and friendships. It also facilitates the inclusion of individuals with disabilities into these groups and offers activities and connection with the other participants. A number of case studies have been reported of individuals (from young children to older adults) who were included in community groups and who made friendships with group members without disabilities (Arsensault, 1990; Perske, 1988; Strully & Strully, 1989).

### **Inclusion in General Classrooms**

One of the primary rationales for inclusion of students with disabilities into general classrooms is the opportunity for these students to interact socially with their peers without disabilities in and outside of class (Stainback & Stainback, 1990). In general, research suggests that positive social relationships did occur between students with and without disabilities (Hall, 1994; Staub et al., 1994). However, there were substantial differences in both the amount and the nature of these interactions experienced by students who had disabilities. The amount and particularly the forms of the interactions and relationships for many students with disabilities with their peers is different from what is typical among students who do not experience disabilities, and it remains unclear which criteria and measures should be used to judge progress toward social inclusion of students with disabilities (Hall, 1994). One conclusion that perhaps can be drawn is that inclusion is sufficient for some students with disabilities to develop typical levels and forms of interactions with their peers, whereas for many students inclusion in typical classrooms is not sufficient, and other strategies must be utilized to facilitate social interactions and relationships. Strategies such as the active promotion by teachers of a relationship between a student with disabilities and a peer or peers is one strategy that appears to have some impact (Cole, 1986; Meyer et al., 1987; Voeltz & Brennan, 1984). The argument has been made for the utilization of strategies that promote positive interactions and relationships for all students, rather than using different approaches for students with disabilities (Uditsky, 1993). Cooperative learning strate-

gies have been identified as holding promise for promoting relationships among all students (Gartner & Lipsky, 1990; Stainback & Stainback, 1990). Using a cooperative learning approach, teachers facilitate all students to teach and support each other and typically focus on participatory learning activities to encourage the active involvement of students in projects.

### Entering the Work World

As with school inclusion, one of the primary reasons for moving individuals from sheltered to regular businesses was the increased social interaction opportunities with co-workers without disabilities that are available in the latter. There is no question that individuals who work in regular businesses have higher levels of social interactions with co-workers without disabilities during their workday than do individuals who work in sheltered workshops. Evidence also shows that co-workers are less involved with employees with disabilities who work in a group than with an employee who is individually placed (Rusch, Johnson, & Hughes, 1990). However, research has revealed that the amount and nature of the interactions among co-workers with and without disabilities were less than among co-workers without disabilities (Chadsey-Rusch, 1986; Lignugaris/Kraft, Salzberg, Rule, & Stowitschek, 1988; Storey & Knutson, 1989). In addition, it was also found that employees with disabilities were less likely to be involved in joking and teasing, social interactions that were found to occur at a high level among co-workers without disabilities (Lignugaris/Kraft et al., 1988).

The role of the job coach has been identified as one factor that impedes the development of social connections between co-workers with and without disabilities (Nisbet & Hagner, 1988). The groundwork for connections among co-workers typically occurs during the first few weeks and months on the job, when a new employee is trained and is helped to understand the workplace culture (i.e., the unwritten rules of fitting in) by other employees. When an agency staff person takes most or all of the responsibility for training an employee with a disability, these initial opportunities are lost. In addition, the presence of a job coach may serve to stigmatize, accentuate the employee's differences, and indicate to co-workers that only individuals with specialized training know how to interact with their new co-worker. There is a growing trend to encourage employees with disabilities to be trained by co-workers and for supported employment program staff to provide input to co-workers when necessary about approaches that may be unique to the learning needs and style of a particular employee (Rogan, Hagner, & Murphy, 1993; Sowers, 1995). Research on interventions has focused almost exclusively on teaching employees with disabilities social skills to use at worksites (Chadsey-Rusch, Karlan, Riva, & Rusch, 1984; Shafer, Brookes, & Wehman, 1985). For example, Breen, Haring, Pitts-Conway, and Gaylord-Ross (1985) taught students with a disability at a work experience a break-time conversation script that they could use with their co-workers.

As stated, the current hope is that the amount and type of social interactions between co-workers with and without disabilities will be enhanced if the new workers are initially trained by co-workers rather than by a job coach. No research has yet been conducted to determine if co-worker training approaches do result in this outcome. It has also been suggested that supported employment staff must focus much more of their time and effort on facilitating social connections among supported employees and co-workers, rather than just on addressing task performance issues. Again, no research is available illustrating the impact of proactive co-worker interaction facilitation.

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## Teaching Leisure Skills

A body of literature illustrates the effectiveness of systematic instruction and adaptation strategies in teaching a wide variety of leisure skills (Baumgart et al., 1982; Schleien et al., 1995; Wehman, 1977).

## THE BUILDING FRIENDSHIPS PROJECT

Each year, approximately 165,000 children and youth survive traumatic brain injuries (TBI) sustained in motor vehicle accidents, falls, sports accidents, and physical abuse (Bush, 1986). Of these children, 20,000 annually are left with long-lasting alterations in social, behavioral, physical, and cognitive functioning (Kalsbeek, McLaurin, & Harris, 1980; Rosen & Gerring, 1986).

The loss of friends, decrease in social activities, and absence of social support that usually accompany TBI can be the most difficult effects for children and adolescents to manage (Singer & Nixon, 1995; Wagner, Williams, & Long, 1990; Willer, Allen, Durnan, & Ferry, 1990). After a brain injury, a student often loses the ability to function effectively in social situations; he or she may behave in ways deemed socially inappropriate (e.g., showing disinhibition, poor social judgment, insensitivity to others, or impulsiveness). Friends may be confused by the student's behavior and may gradually drift away. This problem is only exacerbated when the student has had to miss up to an entire year of school while undergoing rehabilitation. Same-age peers have moved on to a new grade level and established new friends and interests, and the student with TBI may feel left behind.

Just as a child never fully recovers from TBI, the child's friendships may never return to the way they were before the injury. Many survivors of brain injury report that problems with social isolation persist over many years (Thomsen, 1984) and that new problems in the area of social support often develop in the years following injury (Brown, Chadwick, Shaffer, Rutter, & Traub, 1981).

The Building Friendships project focuses on alleviating the social isolation experienced by students with TBI by developing and enhancing school-based social networks. The project uses an adapted version of MAPS for this purpose (Vandercook et al., 1989). The overarching goal of the Building Friendships project is to increase the quality of the student's social life through an ongoing, informal team process designed to bring together and mobilize key people in a student's life. The student, family, peers, and professionals participate in a four-phase process. These phases consist of gathering information, recruiting, conducting an initial team meeting, and holding regular follow-up meetings. Each is described as follows.

1. *Gathering information through interviews with student, parents, school staff, and peers.* Project facilitators conduct interviews to identify opportunities within school and community settings to create new friendships, to enhance current friendships, and to develop increased social opportunities. This information is used as a basis for the initial team meeting (see next step).
2. *Recruiting family members, school staff, and peers for involvement as team members.* Based on information gathered in interviews, key individuals are identified and invited to the initial meeting. The student and family members play the primary role in determining whom to recruit. Facilitators are responsible for making contact with potential team members, who must include peers, extended family, and school staff. In some cases, whole classes are giv-

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en information about the purpose for developing the team; and interested peers are asked to participate.

3. *Conducting an initial team meeting to share information and to create visions for the future.* The team identifies individualized social goals and specific strategies to meet these goals.
4. *Holding regular review meetings.* Every 2–3 weeks, team members meet to review progress, revise plans and strategies, and reevaluate team membership and responsibilities.

Like other person-centered planning strategies, the Building Friendships process strives to create an environment that encourages the student and family to direct all aspects of the planning process. The process combines many of the features of the MAPs (Vandercook et al., 1989) and the circle of friends (Perske, 1988; Snow, 1989) strategies. Several adaptations in these strategies were made in order to accommodate busy schedules of team members and to emphasize social issues and follow-up activities. Following is a description of the adapted process.

### Intent and Structure

The Building Friendships process, like MAPs, represents a dynamic and fluid person-centered planning strategy designed to increase the ability of students and families to guide their own solutions to problems of social isolation. The process emphasizes the importance of including peers as team members as early in the process as possible; hence, potential peers are identified by the student with TBI, family members, and teachers during the second phase.

The original MAPs process consists of seven key questions to help guide efforts of team members in increasing the successful inclusion of students with disabilities (Vandercook et al., 1989):

1. What is the individual's history?
2. What is your dream for the individual?
3. What is your nightmare?
4. Who is the individual?
5. What are the individual's strengths, gifts, and abilities?
6. What are the individual's needs?
7. What would the individual's ideal school day look like?

Whereas MAPs addresses a full range of student-centered issues, the Building Friendships process focuses solely on social issues and is thus of shorter duration. The steps involved in the initial team meeting are described as follows.

**1. Who Is [the Student]?** Participants are encouraged to offer as many words and phrases as they can think of to describe the positive qualities and attributes of the student. These are shared out loud and recorded by the facilitator in colorful markers on a large sheet of paper. This first question sets the tone for the rest of the initial meeting in its upbeat focus on the student's strengths. Importantly, this step can also be emotionally charged for students and families unaccustomed to such an outpouring of positive feedback.

**2. Hopes and Dreams** This question prompts team members to state their hopes and dreams for the student within the social domain. The student is given the opportunity to state his or her own hopes and dreams first. The facilitator checks with the student frequently to make sure that hopes and dreams offered by other team members are

acceptable. The student is the only one who holds veto power for any hope or dream. As long as the student accepts the hopes and dreams offered by others, every response is recorded and nothing is censored. This serves to model a mindset that both empowers the student and expands the team's notion of what is possible. Important goals for the student often emerge from dreams which, initially, might seem unrealistic to achieve.

**3. Circle of Friends** With the information previously gathered, a pre-prepared visual diagram is presented to the group to represent the key people currently in the student's life. This diagram consists of four concentric circles, with the student's name placed inside the innermost circle. Those closest to the student, trusted friends, acquaintances, and paid professionals are all listed on successive circles extending outward from the student. The intent of this activity is to graphically demonstrate the nature of the student's social network. In most cases, students with TBI have only a few close and trusted friends and an abundance of acquaintances and paid professionals in their circle. The goal of the Building Friendships process is to create positive social changes to allow expansion of the student's inner circle of trusted friends.

**4. Goals** The next phase of the first meeting involves identifying several goals toward which the team can begin working. Often these goals are derived from the hopes and dreams created earlier by the team. As in the earlier steps of the process, the student decides whether chosen goals are acceptable. Goals are fluid and can be changed as needed, and it is important to remind the group that more goals can be added in future meetings.

**5. Obstacles** Next the team identifies obstacles to achieving the identified goals. Team members are asked to think of all the reasons why the identified goals are not currently being addressed.

**6. Strategies** The team then brainstorms specific strategies for overcoming the obstacles. Pushing the limits of commonly accepted practices is encouraged to facilitate the emergence of creative, untried approaches and solutions. Strategies might take concerted effort to implement or might be as simple as a schedule change to permit greater inclusion and opportunities with peers—the point is that at this stage, anything goes. To help initiate the brainstorming of ideas, certain strategies were described to team members as examples that have been found useful with other individuals. The following description shows how each of these strategies were used by one or more of the participants in the Building Friendships Project.

*Schedule changes: modifying a student's schedule to increase social opportunities in inclusive settings.* Rather than spend all day in the special education classroom, Janet's team changed her schedule so that she went to recess at the same time as other first graders and went to the first-grade classroom at the beginning of each day for several hours.

*Peer education about TBI: presenting information about TBI to peers, with specific information about their peer's experiences.* In his middle school homeroom class, Richard and his mother presented a slide show about his rehabilitation from a severe brain injury several years earlier. The presentation included slides of Richard prior to his accident, during coma, and in various rehabilitation activities at the hospital. Richard's mother discussed the effects of the brain injury on Richard and their family. Richard and his mother then answered students' questions.

*Organized recreational activities: linking a student with recreational activities in the community (e.g., through parks and recreation departments and the local YMCA).* As a result of his team's brainstorming and exploring of community-based social and

recreational opportunities for focus students, Ted got involved in a church youth group. Joan joined a Camp Fire club, Bob began going to the YMCA with two friends several times a week after school to hang out and shoot baskets, and Ralph and another young man started working out in a gym three times a week.

*Friendship clubs: shifting focus from one individual to a larger group while facilitating and maintaining a general group awareness of and sensitivity to pertinent social issues of group members.* One special education teacher began the Building Friendships process specifically for her student Billy. But as peer interest developed and grew, the focus gradually shifted away from an exclusive focus on Billy. Soon Billy and his peers were meeting once a week to discuss concerns about friendships and were planning dances and other activities to be involved in together.

*Buddy system for getting to and from class and at lunch and recess: asking peer volunteers to assist students who need help getting around the school campus and to spend time with students at lunch and recess.* The facilitator for Helen's team was able to coordinate with other teachers whose students were interested in eating lunch with Helen and playing with her at recess. These artificial situations were helpful in allowing the children to get acquainted with one another and to establish a routine. After several months the peer team members decided that having a schedule was causing problems and was unnatural. The formal buddy systems were dropped, but the interactions with Helen and her peers continued.

*Cooperative learning activities: structuring classroom activities so that groups of students work together toward a common goal.* This strategy was not selected by a student and his or her team. An example of how this might have been used is classroom teaching implementing a process whereby small groups of students would work collaboratively to complete math problems or a science project.

*Social events outside of school: planning a group activity in the community.* Randy's team planned an after-school pizza and bowling party that was very well attended by the peers in the group. This experience served to strengthen group rapport, and it gave everyone an opportunity to get to know one another in a different way outside the academic setting. Randy's joking, usually viewed as inappropriate during class time, was well received and reciprocated in this recreational context.

*Organizational systems: creating compensatory systems for keeping track of important information.* Sally's team helped her create a book with pictures of her friends. Below each picture was the friend's telephone number. Each of the friends also had their own photo telephone books so that they could call one another. Ted's team suggested that he carry around a tape recorder at school. This enabled him to record information such as students' telephone numbers, and was a fun way for him to interact with other students as they taped messages for him.

*Informal weekly get-togethers: lunch at school.* Sam and the peers involved in his team decided they would all eat lunch together once a week. A classroom and the gym were reserved for them, and often they took turns bringing special treats. Sam and his peers looked forward to this special time to play group games and have organized discussions about topics of interest ranging from current events to quality of cafeteria food.

*Classwide activities: disability awareness/community building.* As part of their involvement in the Building Friendships project, the facilitator for Billy's team coordinated a Disability Awareness Week that was set up in the school gym. Each class spent their gym time rotating through various simulation exercises which were designed to provide students with the experience of having a number of different disabilities. The

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facilitator for Mark's team came to his block class several times and guided the student group as a whole through some of the steps in MAPS. This was a unifying experience for the students, and some of the pressure of being the focus of attention was taken off of Mark. Both Helen and Billy's special education teachers had an open door policy in their classroom, which made it very comfortable for students from different classes to come in and spend time with Helen and Billy and the other students.

*Events outside the classroom: attending extracurricular school functions.* Through the work and encouragement of team efforts, Ralph obtained a student body card and attended several school dances with his brother and a few friends. Ed became very involved working on the school newspaper and began to feel more comfortable participating in class field trips, and Randy earned extra money as a track helper.

**7. Action Plan** Finally, the team prioritizes goals and strategies and develops a specific plan that details how team members will achieve their goals. The action plan itself consists of three columns: *What*, *By Whom*, and *When*. The action plan keeps team members clear on tasks and accountable for following through with agreed-upon commitments.

Because each student's situation is unique, the activities and strategies decided upon by the team vary considerably. The following presents a menu of sample strategies that might be included on a student's action plan.

### **Implementation of the Building Friendships Process**

**Students** The Building Friendships process was implemented with 10 students who had survived severe brain injury. School-based facilitators worked intensively with each student throughout the school year. Of the 10 students, there were 7 boys and 3 girls, ranging in age from 7 to 17 (mean age = 11.7). Prior to their injury, 6 of the 10 students were average to above-average students who attended their home schools, performed at grade level, and were not described as displaying behavior problems. The remaining four students were under age 5 and not yet enrolled in school when they were injured. According to parent reports, none of these students showed signs of physical, behavioral, or cognitive deficits prior to their injury.

When they became involved with the Building Friendships project, the students averaged 4.7 years postinjury (range = 2.4–9 years), well past the most rapid period of "spontaneous recovery." As a result of their injuries, they experienced significant deficits in physical, cognitive, and behavioral functioning. They received special education services in resource or self-contained settings. All of the students had experienced a significant decline in their social network. They described themselves as having few, if any, friends.

**Facilitators** For six of the students, project staff facilitated team and peer group development; for the remaining four students, school-based educators were trained to facilitate the process in their schools. The trained facilitators included two special education teachers, a special education consultant, and an educational assistant.

Prior to getting started with their students, facilitators participated in a day-long training session. The training was designed to familiarize facilitators with the general goals, value system, and approach of the Building Friendships process. The steps in the MAPS were detailed as a foundation to the Building Friendships process, and case study information was provided about social issues specific to students with TBI and their families. The training served as an opportunity for facilitators to understand their role in enhancing social experiences for students with TBI and to discuss poten-

tial challenges to implementing the Building Friendships process with their particular students.

**Measures** To evaluate the effectiveness of the Building Friendships process, project staff interviewed students, parents, and teachers prior to and following their involvement in the project. In addition to gathering demographic information about participants, interviewers asked participants to complete several written measures.

Teachers and parents completed the School and Community Activity and Integration Assessment (SCAIA) (Sowers & Powers, 1991). This instrument assesses a student's level of social integration in school and community settings. The measure is administered to a parent for home and community activities and to a teacher for school activities. The measure asks the parent to indicate the number of times, in what context (e.g., telephone call, home visit, neighborhood play, club), and with whom the student has recently socialized. Parents also report how often the student has participated in the activity during the prior month, 3 months, and 6 months. The teacher scale includes analogous questions for school-related activities.

Parents, students, and teachers also completed social validation measures designed to assess their satisfaction with the students' social networks before and after their involvement in the project (5 = highly satisfied). Participants were asked to rate how satisfied they were with the quantity and quality of the students' interactions with peers.

Finally, at the completion of the project, participants were asked to provide their perceptions of the process as a whole. Participants were asked open-ended questions about their satisfaction with the process and its effects on the student.

## Results

Table 1 depicts parents', teachers', and students' mean responses on pre- and postproject measurements for the 10 students involved in the Building Friendships project. As indicated in Table 1, the average number of friends reported by the students, their parents, and their teachers increased from pre- to postassessment. In the majority of cases, students named more friends than did their parents or teacher at both pre- and postassessments. At postassessment, parents reported that their child spent less time in the prior month with peers with disabilities than they had in the month prior to pre-assessment. Parents reported a substantial increase, however, in the number of activities their child did with a friend without disabilities. On the satisfaction measure (i.e.,

Table 1. Results of Building Friendships

Measure	Students		Parents		Teachers	
	Pre	Post	Pre	Post	Pre	Post
Number of friends	5	7	2	4	3	4
Involvement-peers with disabilities			.8	.67		
Involvement-peer without disabilities			4.6	10.0		
Satisfaction	3.2	3.0	2.3	2.8	2.5	2.9

*Note:* Pre (prior to Building Friendships participation) and Post (after such participation) refer to mean responses by students, parents, and teachers about the number of friends of students, the number of activities students participated in, with peers with and without disabilities, and the level of satisfaction with the students' social network.

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satisfaction with the quantity and quality of the student's social network), the mean responses by parents and teachers increased from pre- to postassessment, whereas the students' average responses decreased slightly. Only one of the students' ratings on this measure actually decreased at postassessment; however, because of the small number of students in the sample, this student's scores decreased the group mean.

In postassessment interviews, students, parents, and teachers reported feeling very satisfied with the effects of the process on the students' social networks. Students were seen as having more opportunities to interact with peers and were spending more time with peers in home and school settings. Participants commented that the problem-solving process used in the meetings allowed the group to work collaboratively.

Parents and teachers also felt that the process helped their students feel more positive and confident at school. In many cases, they attributed the changes to the involvement of peers in regular meetings:

Kim just made a complete turn-around. She knows how to communicate now...the meetings were extremely important. I was amazed at how much input we got from the kids. They were saying things that I was thinking but really couldn't say.

One teacher who worked with a student who had a history of aggressive behavior felt that as a result of being involved in the project, her student had learned more positive ways of interacting with peers:

After we started this process David became a new kid...he doesn't have any behaviors that are really violent...kids come up and they want to play with David....He didn't have any friends before, everyone was afraid of him.

## Discussion

Because of the lack of control group data and the variability in responses, the results presented here can be interpreted only as preliminary in nature. However, the results do suggest that after their involvement in the project, students, parents, and teachers reported increases in the number of activities the students did with peers without disabilities and in the number of friends the students had. Parents and teachers also reported increases in their satisfaction with the student's social life.

Results from the Building Friendships project have been encouraging. With minimal training designed to introduce an informal, creative approach for enhancing social participation of students with TBI, facilitators were able to promote positive changes in a limited period of time. The Building Friendships process requires ongoing effort to further increase and maintain its effects. While the facilitator role may decrease in intensity over time, it is likely that some form of continued guidance and monitoring of the team process will be needed. This section highlights additional factors that have been instrumental in the implementation of the Building Friendships process. Issues to be aware of that are specific to working with students who have TBI and their families are outlined, as are other insights gained along the way.

1. At least one adult member of the Building Friendships team needs to have a strong commitment to enhancing the student's friendships. This is absolutely essential to the success of the process. One person's ongoing commitment will help to ensure that necessary follow-through will occur.
2. The building administrator needs to be supportive of the project if team efforts are to succeed. The Building Friendships process introduces new approaches to facilitating social opportunities within school settings. With support of the

process from principals, team members often experience a greater sense of freedom to engage in creative problem solving and activities.

3. Ideally the friendship facilitator is a school staff member, or, at minimum, has close associations within the school. Because each school has its own culture, it can be difficult to implement the process as an outsider. Insider status can be helpful in recruiting team members, organizing activities and events, and maintaining adequate communication.
4. The facilitator needs to keep in contact with team members between meetings to maintain group cohesion and to determine whether any situations have arisen that will prevent team members from following through on specified commitments. Providing such "glue" is a key to success of the process. Linking team members in ongoing communication between meetings serves to deepen feelings of membership, and helps to establish and maintain the group's momentum.
5. Every child is different, so the process must be tailored to meet each student's unique needs. What works for one student may be inappropriate for another. Keeping the process creative, dynamic, and open to variation will further enhance its effectiveness. This flexibility is the essence of the Building Friendships process and helps keep teams from getting stuck in ruts.
6. To the extent possible, Building Friendships should be a student-driven and peer-driven process. Allowing students to direct their own process as much as possible is an empowering experience that is new for many people. Trusting in this approach can serve to strengthen student commitment to the process which, in turn, will result in greater ownership of outcomes on the part of the students.
7. Emphasis should be placed on reciprocity between the student and other peers. Horizontal, not vertical, relationships are the goal. The Building Friendships process aims to facilitate and support interactions among peers that are based on equality of status and are not hierarchical in nature.

### Lessons Learned

Other issues and dynamics that became apparent during the course of the Building Friendships project are important to consider before attempting to increase social relationships for students with TBI. Weiss (1973) makes an important distinction between social isolation characterized by the absence of a peer network and emotional isolation that stems from a lack of deep, meaningful friendships. Early in the process of implementing the Building Friendships project, it became apparent that the friendship-enhancing strategies we were using were designed to address issues of social rather than emotional isolation. In providing a structure for increasing social opportunities with peers, the hope is always that over the long term, friendships will take root and develop.

Awareness of and sensitivity to the issues faced by family members is a critical aspect of the Building Friendships project. For some families, their child's loss of friends is a very difficult and sensitive issue. One parent told us, for example, that becoming involved in the process was frightening at first. For the first time since her son was injured, she was asked to confront the deep sadness she felt about her son's loneliness and to trust that this group of well-meaning professionals and peers might help him reestablish important social connections.

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In some cases, we found that parents were pleased to attend meetings and support school efforts, but were unable to promote interaction in home and community settings. The reasons for their reluctance varied. Some parents were less concerned about their child's social network than they were about academic goals and devoted their necessarily limited energy to helping their child with schoolwork. For others, the day-to-day stresses they faced outweighed their desire to help their child develop friendships. Many of the families we worked with faced enormous financial and emotional drains on family resources. It is critical that schools begin to view their roles to include active, out-of-school supports. This new view may include the allocation of staff who are able to spend time away from the school building, during after-school hours (including evenings and weekends), to provide direct support and assistance to students related to leisure and social activities (see the next section, which describes the Community Bridge-Builder Project). Schools may also include providing financial resources directly to students and families that will assist in the cost of out-of-school community activity participation, including the cost of transportation and leisure activities.

### **CONNECTING TRANSITION-AGE STUDENTS TO YOUNG ADULT LEISURE ORGANIZATIONS AND ACTIVITIES**

With the assistance of the New Hampshire Natural Supports Project (Sowers, 1994), Nashua High School in Nashua, New Hampshire, conducted a survey of students with significant developmental disabilities who had departed from school services between 1989 and 1991. Interviews with the school leavers and their families revealed that their greatest current concern was the lack of social and leisure activities in which the young adults engaged and their lack of friends and social acquaintances. With the exception of the Special Olympics, leisure activities for most of the students were limited to those done with their family.

In response to this survey and with a desire to enhance the postschool social lives of current students, Nashua High School hired a community bridge builder to assist students with significant developmental disabilities who were 18-20 years of age to participate in community leisure and social activities. The community bridge builder was hired through a small grant received from the New Hampshire Department of Education. The goal of this person was to facilitate each student to participate in at least one typical community organization or activity that provided the opportunity for the student to develop relationships with the other members of the organization or activity. The role of the community bridge builder was not to do activities with the students, but to facilitate and assist each student to become connected to and supported by the members of a typical leisure organization.

To fill the community bridge-builder position, the school district specifically looked for a person who met the following criteria. 1) The person had to be very familiar with and well-connected to the local community. A person who has lived for many years in a community and who is active there is able to quickly identify the organizations where the greatest opportunities for social connections exist. Such a person will also frequently know one or more individuals who participate in an organization there, thus making the approach to these individuals about including the students and young adults much easier and more natural. 2) The person had to be outgoing and able to easily communicate with and relate to a wide variety of individuals. Again, the role of the bridge builder is not to do activities with students, but to serve as a bridge between the

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students and individuals who belong to organizations and participate in activities. The activities to which students are connected are driven by their individual interests and thus include a wide array of groups and types of people who participate. A shy person or one who feels comfortable interacting with only certain types of individuals will have a difficult time successfully taking on this role. 3) The person had to be able to work afternoons, evenings, and weekends. Most young adult and adult social activities do not occur during the typical school day. Rather, these activities occur when young adults are not going to school or working. The bridge builder must be willing and able to work a schedule different from other school personnel. This schedule flexibility, of course, must also be accommodated by the school district. The funding provided to Nashua High School from the New Hampshire Department of Education permitted the hiring of an individual into the community bridge-builder position at the wage paid to a special education aide. The individual hired into the position was a young woman who had worked as an aide at the high school for a year, who knew the students and their families, and who was a native of Nashua and well connected there.

The Nashua community bridge-builder project was conducted for 1 year. In addition, other school and respite care organizations in New Hampshire are implementing similar projects. The following provides a description of strategies and recommendations that derived from what was learned through the Nashua High School and other subsequent community bridge-builder projects.

1. *Investigate and develop a written document describing local community social and leisure organizations and activities.* Every possible typical organization and group should be included, not only the most well-known or formal organizations. Include special interest groups (e.g., model train organization, book discussion groups, poetry groups, hang glide associations). In other words, don't focus on groups or activities based on a preconceived notion of what individuals with disabilities can do or would want to do. Also, bridge builders do not have to wait to begin connecting individuals to activities until every single group has been identified and surveyed—get the list going and let the individual's interest drive your further investigation. Community bridge builders should be faithful readers of the social and community news sections of their newspapers and bulletin boards posted at community organizations and businesses.

Again, developing a list and description of local community activities will be easier for bridge builders who are already very familiar with a community and well connected there. In investigating and compiling information for the Community Activity Guide (a name some of the bridge builders have used), bridge builders should attempt to actually meet with someone from the organization and attend an activity. Doing this will permit the bridge builder to begin to develop a connection with the organization and to gain the kind of information needed to determine if it is a place that will be supportive of a student and will provide opportunities for connections and to plan for facilitating these supports and connections. During initial contacts with an organization, a bridge builder should not emphasize his or her role as working for and with students with disabilities. In fact, we have found that a better title for a bridge builder is community liaison, a more common and generic term. The bridge builder from Nashua High School typically described her role as representing the school district's goal to develop and expand their connection with community businesses and organizations and to involve students in a variety of ways in community activities, including assisting students to become active members of positive and adult social and community organizations. The written document should have a brief description of each organization/activity, including the specific types of activities that occur there, the type of

members that belong and attend events (e.g., age, gender, how supportive they seem to be), cost, schedule of activities, and accessibility.

2. *Gain initial support of family.* Most of the families were excited by the prospect that the school was going to provide resources to assist their sons and daughters to become involved in leisure and social activities. However, most of the families also assumed that this meant a school staff person would accompany their children to these activities on an ongoing basis. The families had a certain degree of fear about the prospect of having their children belong to and participate in typical social activities "on their own." Parental concerns included fears that the children's physical safety was threatened, that the young adult would be ridiculed or shunned, and that the young adult could not perform or participate in a meaningful fashion without outside support. The bridge builder found it important not to insist that the families make a full commitment to the idea that their son or daughter would eventually be supported naturally in order to proceed. The bridge builder assured the families that she would never place the student in a situation that was deemed unsafe or unsupportive and that she would provide as much support as needed to ensure that the student was safe, both physically and emotionally. The bridge builder discovered that when she was able to describe for the parent a specific organization, the individuals who participated there, their commitment to their son or daughter, and a plan for ensuring his or her safe and active participation, all of the families were willing to support the plan.

3. *Identify the types of activities the individual enjoys.* Some students have a very clear idea about what they want to do as a community leisure activity. One student was clear that she wanted to take horseback riding lessons. For students with clear leisure goals, the bridge builder can begin to immediately plan with him or her how to achieve this goal. However, many students do not have such a clear idea. For these students, bridge builders need to help them identify their leisure interests by asking such questions as these: What do you like to do for fun? What do you do for fun when you get home from school in the afternoons? What did you do yesterday afternoon, and/or what are you going to do today when you get home? What do you like to do on weekends? What did you do last weekend, and/or what are you going to do this weekend? Do you have any hobbies? Are there any classes at school you have really liked? With the assistance of the bridge builder the student should write these things on a sheet of paper with the title "Things I Like and Things I Like To Do For Fun." If a student is not able to understand these types of questions or to readily communicate more than basic needs, then it will be necessary to ask these questions of the family.

After the student has identified his or her interests, the bridge builder can then go through the Community Activity Guide with him or her, describing those organizations and activities that reflect his or her interests, and the student can choose a few that she or he wishes to investigate in order to decide which one to pursue. Students may also wish to spend time going through other sections of the guide and hearing about organizations and activities that may not have anything to do with his or her current interests. This effort may spark a new interest.

4. *Identify what the student will need to attend and participate in an activity.* The bridge builder should assist the student to think about the things he or she will need. We have found it helpful to begin with the following list: money, transportation, clothes, equipment, learning how to do the activity, Meeting and Getting to Know Other People. The student, with the assistance of the bridge builder, lists the things that are needed and then brainstorms possible ways these needs can be met. Money is typically a major issue. If the student works, he or she should be encouraged to contribute as

much as possible to the cost involved in joining and attending. Social Security income should be another resource that is considered. Of course, using these resources often is not simply up to the student, but must be negotiated with the family.

This is a good time for the student and the bridge builder to meet with the student's family. The student should lead the discussion to the greatest extent possible. The student should give his or her parents the list of interests and the specific organizations and activities he or she wishes to explore. The student should also give his or her parents the list of needs and supports that was developed. The bridge builder should then facilitate a discussion with the family about the assistance that the family can and will be able to provide. Again, money is often a major issue. The bridge builder needs to encourage a family to permit the young adult to use his or her own resources for these purposes if he or she so chooses, while at the same time not making this a requirement for participation or a point of contention. Other resources should be offered if the family is unable or unwilling for the student's or their own resources to be used to pay for any or all of the costs. Other resources that have been tapped include The Developmental Disabilities Agency in New Hampshire, which provides a small amount of Family Support funds and respite care dollars to families. Families are permitted to use these dollars in any way they wish, including paying for memberships and other expenses involved in leisure activities for their sons and daughters. A few districts have been willing to pay for some of these costs, especially if the student happens to attend the activity during regular school hours or if the student attends school fewer hours because of his or her involvement in the activity during the evening or weekend that is paid for by the school. Finally, a number of health clubs provide a certain number of students (these arrangements were established not as "special" programs for students with disabilities, but for all students) with the opportunity to exchange a small number of hours of work weekly for a membership.

Transportation is also another major logistical issue faced by students wishing to participate in regular and typical community activities. Of course, whenever possible the student should use a public bus. However, the availability of public transport in most communities is extremely limited, especially during the hours when many social activities take place. Many families are not able (because of schedule restrictions) or wish not to provide transportation. This is especially true for parents of older individuals—they do not have the energy to leave the house after dinner to drive across town and then to return several hours later to pick up their son or daughter. Again, bridge builders should try to walk a line between looking for other options and encouraging families to provide some transportation because of the importance of the activity in their son's or daughter's life. We have found it useful for bridge builders to provide transportation for several weeks. This provides the bridge builder the opportunity to talk with and reassure the student before going into the activity and, at the end of the activity, to check in on how things are going. The bridge builder may be able to identify a person in the organization who can give the student a ride to and/or from the activity. This may be a person the student meets and gets to know. The student (with help from the bridge builder) could ask about getting a ride. A group leader may also be approached about identifying individuals who live in the same vicinity as the student and might be asked about a ride, or a ride request notice might be put up on a bulletin board. The student should offer the individual payment for providing transportation. Again, families may be leery about allowing their son or daughter to obtain a ride with someone they do not know. Most families seem to feel most comfortable with a female and with someone whom the student and bridge builder have gotten to know over sev-

eral weeks or months. The issue of car insurance and liability are often raised when attempts are made to recruit someone to help provide transportation. However, it is important that these arrangements be viewed not as a program activity, but simply in the same way as a similar arrangement made by any person getting a ride from a friend or acquaintance (e.g., when typical students get rides with each other to school or to an after-school event, the issue of insurance is rarely raised).

The student, with support from the bridge builder, should have the opportunity to visit and observe several of the possible organizations or activities in which she or he might be interested. The manner in which this is arranged depends on each organization. For example, health clubs routinely give tours to interested individuals, and the student should go on a tour like any one else. A young adult interested in an aerobics class may choose to observe it for short period of time, to talk with the instructor, or to go one time and try it out. Once the young adult has observed each of the possible groups, he or she will choose which one to attend.

5. *Facilitate the young adults' participation and connection.* Once again, the role of the bridge builder is not to do activities with young adults, but to actively facilitate their connection to typical members of groups and to gain support from these members. This does not mean simply getting young adults into an organization and activity and hoping that all goes well. Rather it means proactively identifying individuals with whom the person might connect and receive support and providing the assistance for the support and connection to successfully occur. There is no formula for active facilitation—each young adult and each organization and activity dictates the kind and amount of facilitation needed. The following two case descriptions show very different kinds and amounts of facilitation given to two young adults by a bridge builder.

David had a chance to tour a small weightlifting club that was owned and run by two brothers, one of whom was Greg. Greg was not told by the bridge builder that David experiences a significant cognitive disability before meeting him. The bridge builder did tell Greg that David loved weightlifting (he lifted at home) and wanted to see if he would be interested in joining a club. Greg and David seemed to really connect at their first meeting, and David said he very much wanted to join the club. The bridge builder met with Greg and explained how enthusiastic David was and that he was going to join the club. She explained that he probably would need someone with him for several weeks to show him how to use the club and equipment and that the best possible person would be someone who knew the club well, and she asked if he knew of a member who might be able and willing to work with David once or twice a week. Greg said that he would like to be the person and he volunteered (without the bridge builder's asking) to spend 2 hours a week, twice a week with David after his shift at the club usually ended—this would allow him the time free from his other duties. This arrangement continued for several months. Transportation was paid for by the school program. At the end of the school year, David was able to use the club fairly independently and he was well connected to both owners and other club members and received any help he needed from them. He was so clear with his family of his desire to continue to attend the club that they readily agreed to transport him.

Sheila had never done aerobics before, but wanted to give it a try (she had seen people doing it and she knew it was a "cool" thing to do). The bridge builder had chatted with the aerobics teacher several times and thought she would be a supportive person. She also thought that the people in the class (it was one that had been ongoing for a long time, with a core group of regulars) would be supportive. The group did low-impact aerobics and emphasized the chance to move around a little. The bridge builder decided to sign up for the class herself, along with Sheila. They both went together for several weeks, the bridge builder helping Sheila to understand the basics of where to stand (and to stay in roughly the same place) and other social etiquette of aerobics. She practiced with Sheila outside of class to show her how to do some of the basic moves and how to watch the instructor and copy her. The bridge builder introduced herself and Sheila to other members of the group when the opportunity presented itself and was natural (e.g., standing next to the soda machine after class).

After several weeks Sheila felt comfortable in the class, and the instructor and many of the class members knew her and were comfortable with her. The bridge builder kept Sheila's mother informed about how things were going and took time after bringing Sheila home to share stories about what had happened that night and about the people in the class. Sheila's mother saw her enthusiasm and felt that she knew the class and that it was a safe and supportive place for her. The bridge builder then asked Sheila's mother's permission to begin to gradually spend less time with Sheila—her mother agreed. The bridge builder told the instructor that because of schedule constraints, she was not going to be able to attend the class regularly any more, but that Sheila wanted to keep attending. The bridge builder told the instructor that she would continue to drop off Sheila and pick her up and would chat with the instructor about how things were going. The instructor said that Sheila sometimes would wander into other people's areas and that they moved for her. The bridge builder suggested that others should simply remind Sheila when she began to stray to move back to her own area (and to point to where it was).

The bridge builder stayed to see how this process went—when Sheila started to wander, the instructor looked at the bridge builder, who nodded to encourage her to say something to Sheila. Sheila moved back to her area and all went well from then on. For several weeks, the bridge builder walked in with Sheila, stayed until the class was under way, and checked in several times during the evening. She then began to spend less and less time there until she was finally only dropping Sheila off and picking her up without going into the building.

Table 2 lists the activities in which students participated before receiving assistance from the community bridge builder. Two students participated in no organized leisure activities with or without their families. One student participated only in church-related activities, but she was always in the presence of her family. Another student only attended a special summer camp. Two students were active Special Olympics participants, and one these students also attended Sunday church services

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Table 2. Activities of students before and after community bridge-builder project

Student	Preproject activities	Identified interests	Postproject activities
1	Church activities with family	Animals—horses in particular	Volunteered at horsebacking farm and took lessons—not “therapeutic” or “special” program
2	None	Books, history	Volunteered at Nashua Historical Society helping to set-up pictures and slides for displays
3	Special summer camp	Dance, music, theater	Took performance dance class
4	Special Olympics	Sports, weightlifting	Joined and went to weightlifting club several times weekly
5	Special Olympics, church with family	Sports	Joined and went to health club several times weekly
6	None	Socializing, hanging out	Joined and attended weekly low-impact aerobics group

with his family. In addition, none of the students and their families indicated that the student did any activity with a person without a disability considered a “friend” over the prior year. Only one of the students and his parent reported that he had done a social activity (other than Special Olympics) during the prior 6 months. Table 2 also provides a brief description of the primary area of interest identified by each of the students and the activity in which the community bridge builder assisted them to become connected.

## CONCLUSIONS

Those individuals involved in attempting to assist people with disabilities to develop real social connections and friendships understand this is probably the most difficult challenge we face. At the same time, this goal is truly the most important and is at the heart of all other initiatives, including school inclusion, employment, and living in typical neighborhoods—we can achieve all of these objectives, but if people still don’t make friends with their school peers, co-workers, and neighbors, what have we really achieved? In fact, the actual achievements in the area of friendships have been modest. We should not be surprised, given the relatively small amount of attention that has been and continues to be focused on friendships and leisure participation as compared with academics, functional skills, employment, and independent living.

The high school in which the community bridge-builder project was conducted had a sincere desire to assist their students in enhancing their participation in typical community activities and in connecting socially with young adults who did not experience disabilities. The district planned to continue the position of bridge builder with their own funding after the grant was completed. There were budget reductions, however, and the district had to weigh where their resources would be allocated. The decision was made that the priority was for aides to devote their time to other activities (academics, functional skills, employment) and that the aide who was the bridge builder would not be able to continue these activities to any substantial degree. This is not an indictment of this particular district, but rather of society’s perspectives regarding the value of these activities and regarding what is needed and should be done to help young people with and without disabilities to achieve full and satisfying lives in terms of their friends and social activities.

There has been decreasing importance placed on the value of friends and connections. This has been a natural accompaniment in a mobile society in which the idea of putting down roots is almost a thing of the past. Careers and obtaining financial security (which seem to have a much higher standard than in times past) now seem to be the primary driving force. In this context, it should not be surprising that special education does not invest much time and resources on social and friendship issues. It should also not be surprising that it is hard to connect people with or without disabilities in this social context. There is the beginning of understanding that focusing on school inclusion may not be the most fruitful approach for achieving meaningful education inclusion for students with disabilities. Rather, the focus must be on school reforms that are aimed at making education more successful for all students—that returns schools to caring and supportive places for all students, including those with disabilities. We are beginning to understand that it may not be the best strategy to encourage businesses to support individuals with disabilities when they are not particularly supportive of any employee. Instead we need to focus greater amounts of our expertise and energy in helping businesses value diversity of all kinds and supportive workplaces for all employees. We need to begin to apply this approach to the area of friendship and social connections—to focus more of our energies on the bigger issue of how to facilitate and reinforce in our families, schools, neighborhoods, and communities the value of connection, support, and friendship.

The call for special education and rehabilitation personnel to begin to view their role as larger change agents does not obviate the need to continue facilitating social connections and friendships for the individuals with disabilities whom we know and to whom we provide "services." In fact, we must increase our efforts in this regard. Schools and adult resources are limited and are becoming more limited, and there will need to be prioritization of what areas are most important. Schools and adult programs should not view leisure participation and connections as extra—not a goal for when other individualized education program goals permit, but as a priority. Again, this focus should not be only for students with disabilities, but for all students. This suggestion is not given lightly. To make this commitment requires a significant change in how the American educational system views its role. Again, there is a growing consensus for the need for widespread and basic school reform, within which schools are examining their missions and practices.

The general lag in progress in the area of building connections between people with and without disabilities may in part also be attributable to the generally held belief that connections and friendships should happen "naturally." We understand and feel comfortable with the notion that individuals (both those with and without disabilities) need lots of assistance and support to learn academics and functional skills and to pursue careers. However, we feel uncomfortable actively facilitating social connections and friendships. When attempts have been made to proactively intervene to develop friendships between individuals, we are often frustrated that our typical ways of controlling and programming often are not "successful." Uditzky (1993) made a compelling argument that friendships cannot be engineered. In fact, we need to actively facilitate increasing the opportunities to bring people together. This includes ensuring that individuals participate in typical organizations and activities. We also need to help actively bridge relationships between individuals with and without disabilities—helping each to communicate mutual interests, helping individuals with disabilities to understand social mores and ways of interacting, and helping individuals without disabilities to understand how to relate to and communicate with the individual with disabilities.



At the same time, we should not expect quick successes from these efforts. Friendships take time (not just weeks and often not just months) to develop, and we should not expect that friendships will always or will even usually take hold—they do not always succeed for any of us. Given active facilitation, two individuals can decide if they wish to be friends, and we cannot and should not try to engineer that part of the friendship process. If two people decide not to be friends, we should not perceive of our work as a failure—we have helped them participate in the typical friendship development process. We must stop viewing the assistance we give as programs and interventions with 1-month, 1-year, or 3-year evaluation deadlines after which we decide, based on counts and numbers, if we were successful and if we should continue with the program.

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**APPENDIX B: BUILDING FRIENDSHIPS MANUAL AND VIDEO**

# **Building Friendships:**

## **A Guide for Enhancing the Peer Relationships of Students with Traumatic Brain Injuries**

**Judith Voss, M.A.  
Elizabeth Cooley, Ph.D.  
Ann Glang, Ph.D.  
Tuck Stevens**

**Teaching Research - Eugene**  
A Division of Western Oregon State College

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## Table of Contents

### Introduction

- a. How to use this guide
- b. Utility of the process
- c. Person first language
- d. Keys to success

### I.) Social Issues Faced by Students with TBI

- a. Loss of friends
- b. Physical, cognitive, & psychosocial effects
- c. Other Issues: embarrassment, peer influence, promoting understanding

### II.) Role of the Facilitator

- a. Making the Process Work
- b. What does a Friendship Facilitator do?
- c. How to get Started
- d. What a facilitator is not
- g. Who should facilitate?

### III.) History of MAPS & Circle of Friends

- a. History of MAPS
- b. Original intention of MAPs
- c. Steps of MAPS
- d. Circle of Friends

### IV.) Steps of the Building Friendships Process

- a. What Makes it Work
- b. Who is Served
- c. Agenda for the First Meeting

### V.) Recruiting Participants

### VI.) Benefits

# Guiding Beliefs for Building Friendships

- Friendships are essential to quality of life.
- Everyone has something to contribute to a friendship.
- Everyone is entitled to the support that friendships provide.
- Sometimes friendships require extra help to get them started.





## Introduction to this Guide

Friendships enrich our lives. For a number of years, researchers have been studying the relationship between the lack of friends and illness. Without friends, any of us are at increased risk of developing physical, social, and emotional problems. In school settings, students with few friends often have higher rates of behavioral and learning difficulties.

There is a growing recognition among educators that academic achievement has a great deal to do with social development and adjustment. Positive social experiences with peers are often at the root of a student's feeling of acceptance. Finding ways to address social issues in the school environment can be challenging, but is very beneficial to students who are in need of support. Friendships help students feel accepted and more confident that they are valued by their peers.

For many children and youth who have experienced a traumatic brain injury (TBI), one of the most devastating long term effects is the social isolation that often occurs following the injury. For a variety of reasons related to the injury, students with TBI frequently lack meaningful friendships. These same students often miss out on or are unable to seek opportunities which lead to full participation with peers in school and community settings. The social isolation that results from a lack of friends can lead to numerous issues for students with TBI and their families.

The Building Friendships process was developed as a way to increase social experiences and social opportunities for students who have TBI, within the school environment. This guide is the result of a three year project. Its purpose is to provide "how-to" suggestions and information for others who believe that students with TBI can develop and maintain long-lasting relationships with their peers. The goal of the suggestions we have provided is to help you create a context from which friendships can develop.

It is unrealistic to believe that anyone can make friendships happen for anyone else; however, it is quite possible to set the stage for friendships to develop naturally. This guide is all about ideas,

suggestions, and directions for facilitating social situations in which the development of mutually satisfying relationships among students with TBI and their peers becomes possible.

### How to Use this Guide

The information presented in this guide is intended to serve as a springboard. There is no definitive "right" way to facilitate social relationships. This guide provides creative suggestions based on our experiences which we hope will be of use to others. The Building Friendships process is a form of person-centered planning based on MAPS and Circle of Friends, both of which will be described in Chapter III. The step by step information provided within can be used as a starting point, but each situation is unique, and it is important to use this information as a guide rather than a formula.

### Utility of the Process

It is important to note that while this guide is focused on students with traumatic brain injuries, the process and ideas presented will generalize to **anyone** who needs support of any kind, regardless of age, ability, or circumstance.

The Building Friendships process is a group problem-solving tool that can be useful for entire classrooms as well as individuals. It is a flexible process that has been developed with the recognition that school personnel are often operating at maximum capacity with very limited time and resources. Therefore, it is our hope that each person will take from this guide what is useful, and will adapt the process to meet individual situations. The adaptability of the Building Friendships process is one of the features which makes it work.

### Person First Language

Most people do not want to be described as a disability. Labels are tools used in complex service systems to describe problems, not people. Saying "Mike is a TBI student" sends a very different message than saying, "Mike is a student with a traumatic brain injury." Our language has a profound affect on how others see and

feel about someone who has survived TBI. As such, we have made every effort to present the person before the label throughout this guide. In Section III, The Role of the Facilitator, and Section V, Recruiting Participants, we address how best to represent students with TBI more fully.

### Keys to Success

In developing this material, three elements have emerged as being critical for the success of the Building Friendships process.

- First, is the willingness of at least one person to commit to follow through with the the Building Friendships process.
- Second, is the capacity to believe wholeheartedly that meaningful relationships between diverse people is possible.
- Finally, creating a sense of 'community' among a group of individuals who may not naturally seek friendships with one another is the key to all possibilities in the social realm.

Each of these three aspects will be discussed more fully within subsequent sections of this guide.

## **Section I:**

### **Social & Emotional Issues Faced by Students with TBI**

*Before Bill sustained a traumatic brain injury following a car accident he was an honor student who was identified as talented and gifted. Bill was extremely popular with peers, and was very active in school clubs and sports. After the accident Bill remained in a coma for three months. During that time school friends came to see him, but the visits became less frequent, until gradually friends stopped coming.*

*When Bill came out of the coma he had to relearn how to talk, feed himself, and use the bathroom. When he returned to school nine months later he required the use of a wheelchair, and his speech was difficult to understand. He no longer attended regular classes, and sometimes Bill pinched people, pulled their hair, or made loud noises. The students remembered Bill, and he remembered them. But beyond greeting Bill in the hallway in the morning, there was no communication or interaction between them.*

**People who are brain injured say that surviving a traumatic brain injury is like dying as one person and being reborn as another.**

This concept cannot be overstated. TBI often results in profound alterations to the individual's physical, social, and emotional being. This profound change is responsible for many of the difficulties associated with social relationships following TBI.

It is important to understand some of the reasons why peer interactions tend to diminish for students who have experienced a traumatic brain injury, and why new relationships are often slow and difficult to develop. While the specific issues will vary from person to person, the following areas of concern are most commonly recognized. Understanding these dynamics can be very beneficial when attempting to improve relationships between students with TBI and their peers.

#### Loss of Friends

Bill's story is but one example of the often tragic aftermath of a traumatic brain injury. Prior to acquiring a traumatic brain injury, most students had developed rich friend and social relationships. Immediately following a TBI, close friends tend to remain involved

and concerned. Yet as time passes during a lengthy recovery, and as changes to the injured student's physical and emotional being become more obvious, even long-standing friendships often fade.

As in Bill's story, profound changes have occurred, and old friends often feel confused and uncomfortable. The "new" Bill is not at all like the "old" Bill. It is often difficult, particularly for children and young adults, to know how to respond to their friend who is so changed. There is often a profound sense of loss experienced by the friends, as well as by the student with TBI. Despite the shared grief, the injured student and friends are often unable to express this sense of loss, or do anything about it.

More than likely, parents are too overwhelmed by the trauma of their child's injury to have the energy required to help maintain and support pre-existing friendships. Anyone who has dealt with a traumatic brain injury, whether parent, teacher, injured student or friend, will testify to the difficulties involved in reestablishing a mutually supportive relationship with, in essence, a person whom you have not previously known. Without support in this process, friends tend to drift away.

"I guess the biggest disappointment was...when...his friends found out it was more of a permanent situation, and they just kind of faded away from us.... They just stopped coming around, didn't see him anymore, and that was kind of heartbreaking." (Parent of a child with TBI)

### Physical, Cognitive, & Psychosocial Effects

Of the numerous physical, cognitive, emotional, and behavioral changes that are characteristic of a TBI, it is often difficult to distinguish between those that are neurologically based, and those that result from psychological effects. In addition, it is difficult to predict which areas might continue to show improvement, and those areas that will remain permanently changed. The following paragraphs represent some of the most common long term characteristics of a TBI that may interfere with the maintenance or development of meaningful social relationships.

- **Physical effects:** Long term physical effects of a TBI may be non-existent or minimal, such as a limp on one side of the body or slightly altered speech. On the other hand, a TBI might leave someone unable to control any of their bodily functions or to speak.
- **Cognitive effects:** Many TBIs result in difficulties with retention, and other aspects of memory loss. Understandably, numerous learning challenges might present themselves. Here, too, the degree of cognitive interference can vary from mild to severe. It is important to consider that most people who experience a TBI remember themselves as they were prior to the injury. This, in turn, can lead to depression, anxiety, and other psychological issues.
- **Psychosocial effects:** Other characteristics common to TBIs that may interfere with social relationships are the inability to inhibit inappropriate behavior, lack of impulse control, low frustration tolerance and anger control, reduced judgment and motivation, and the tendency toward self-absorption. Often there can be a loss of understanding or ability regarding how to function within social norms.

### Other Social Issues

Aside from the direct effects of a TBI there are other social issues to be aware of. The following represent some of the most common situations one might encounter during the course of facilitating an increase in social experience:

- **Embarrassment:** The student with TBI might want and appreciate the type of support necessary to develop a more satisfying social life. Yet often there can be an accompanying sense of deep embarrassment associated with being vulnerable in front of peers, and being the focus of attention. There also can be a great deal of anxiety for the student who fears that no one would want to be a part of a supportive network. It is important to be aware of, and sensitive to, these very real apprehensions, and to honor the student who is not ready to be involved in the Building

Friendships process. On the other hand, a student who initially feels very apprehensive can often work through these feelings and end up thriving from the support provided through the process.

- **Peer Influence:** Dealing with the impact and social influence of peers may present more significant challenges. For teenagers in particular, engaging in reckless behavior with friends might have resulted in a TBI. For some students, nothing less than returning as a full member to their former peer group will satisfy the yearning for meaningful social interaction. Sometimes, former friends who no longer accept the student with TBI can influence others, either consciously or unconsciously, to shun the student with TBI. There are no easy solutions to these issues; however, knowledge of such dynamics can form a basis for working through the challenges in partnership with students, parents, and other concerned individuals.
- **Promoting Understanding:** Despite the many social challenges following a TBI, it can be easier to promote understanding and to gain an empathetic peer group for someone with TBI than for someone who has a congenital disability. Providing information about a student's injury, dispelling myths, and creating a safe place to ask and answer sensitive and difficult questions can all lead to a level of acceptance necessary for friendships to develop. Peer groups have been impacted deeply by listening to students and family members talk about the experience of receiving and surviving a TBI. A personal identification becomes possible which does not exist in the same way as imagining someone born with a particular disability. Sharing information with peers often results in a feeling of "it could have been me," which in turn creates a level of understanding conducive to positive interactions.

The information in this section has been presented as a way of bringing into focus some of the main social issues following a traumatic brain injury. Emphasis is placed on working through these issues by providing a forum for ongoing discussion, rather than arriving at any easy 'answers.' Through the Building Friendships process a core group is developed, and a container is created for sharing and problem solving. Facilitating this type of interaction is

the basis of Building Friendships. In the next section the facilitator role will be explained.



## Section II: The Role of the Facilitator

*Jim is a student in Maria's class. Several years ago, he suffered a traumatic brain injury . Since returning to school, Jim has had problems in nearly all facets of the school day. Jim's ability to successfully move through the school day is hindered by his inability to participate appropriately in school activities. Staff and students alike are afraid of Jim because of his violent outbursts.*

*Fortunately for Jim, Maria sees beyond his anger. She sees a young boy who is socially ostracized, isolated, and extremely lonely. Maria knows that unless someone is willing to spend time helping Jim learn how to deal with these issues, the issues will persist. Maria cares about Jim, and wants to see his quality of life improve.*

*Maria makes a commitment to become a friendship facilitator for one school year, but wonders about the responsibility that goes along with the commitment. Is she trained enough? Will she have the time? What about all the other students in the class that need her attention? By the middle of the year she has found ways to adapt her style of facilitation to accommodate her situation. She is confident in her role, and sees great improvement in Jim.*

Friendships between students who do not naturally interact with one another seldom develop on their own. In order for such friendships to develop, at least one person in the school setting needs to believe in, and make a commitment to actively promote social opportunities for students like Jim. Skillful facilitation is a most important link in bringing together students with TBI and their peers.

- A facilitator is someone who represents a student with TBI to others in a positive way (ambassador), and
- provides a link between people who may not naturally come in contact with one another (bridge builder).

With minimal preparation and training, virtually anyone can take on the role of friendship facilitator. The role itself is not complex, and is relatively easy to assume. Classroom teachers, aides, counselors, itinerant school personnel, parents, and even motivated students can become friendship facilitators. With experience, one soon realizes that the facilitator role is multi-faceted, and that dealing with human dynamics in a group context is challenging and exciting work.

## Making the Process Work

Based on our experiences, the three most essential requirements for successful facilitation are:

1. **Commitment** to the long term process of facilitation
2. **A fundamental and firm belief** that meaningful, reciprocal relationships between people of diverse abilities are entirely possible
3. **The ability to build community** by breaking down barriers between people to work toward common goals

### **Commitment**

As a facilitator, it is quite easy to set up situations which look good on the outside, but have little substance on the inside. For example, you may arrange for a student with TBI to eat lunch with a group of his peers. Being physically close to a group of peers may give the illusion of social involvement. However, if the goal is to facilitate mutually satisfying relationships between the student with TBI and his peers, you should be prepared to make a long-term commitment to this process.

The development of rich and meaningful friendships require a different level of facilitation. Most of us don't make "best friends" overnight. Friendships require time and effort even under the best of circumstances. Before undertaking the process of facilitation, it is important to understand that the "richer" the desired relationship between a student with TBI and his peers, the longer the process is likely to take.

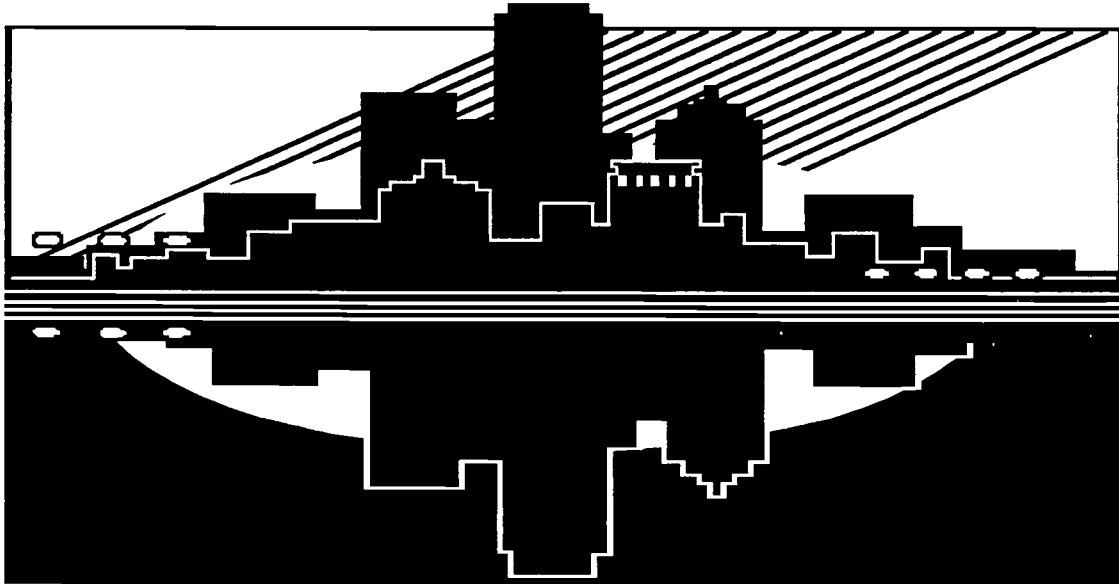
These are distinctions which become more apparent as one gains experience in facilitation. Unless efforts of facilitation have been able to achieve a deeper level of interaction among the students involved, pulling out of the situation prematurely most likely will result either in a regression back to the former state of interaction, or a stabilizing at a superficial level.

## A Firm Belief

A facilitator who believes that Bill or Jim's physical and/or cognitive disabilities would stand between their joining the scouts and attending camp-outs with friends will have a difficult time, at best, promoting such activities. It is important for anyone undertaking the role of facilitator to examine his/her own personal values and belief systems, and to notice the places where the line is drawn regarding attitudes and opinions about inclusion, both in schools and communities, as well as in personal relationships.

## Community Building

Facilitation does not require a special degree or extensive training in counseling and group dynamics. However, it is very important that the facilitator become familiar with how to manage group process. In many respects, facilitation is about creating a meaningful, fun, engaging experience for all participants. It is about breaking down stereotypes and awkward feelings, and promoting a sense of group rapport, cohesion, and belonging. As such, it is also extremely helpful to be familiar with the age group of the peers involved.



## What Does a Friendship Facilitator Do?

The following list which describes the role of facilitator is the result of "brain-storming" by several facilitation training groups comprised of educators and parents. This process demonstrated one of the most exciting aspects of facilitation, that there is no single or absolute process in facilitation. Facilitators are able to bring who they are into the role, making each experience of facilitation a unique and creative process. It is important to note that this list is not exhaustive; that is, each person coming to the role of facilitation most likely will be able to add to this list based on individual experience. This list is intended to provide an overall 'feel' for the many different aspects of facilitation. While all of these aspects of the role are important, we have highlighted several of the most fundamental elements of the facilitator role following the list:

### **A Facilitator is One Who:**

#### ***Makes initial contacts - recruits participants, including peers***

The facilitator is responsible for gathering enough up-front information about potential participants to determine who the most appropriate people would be to invite to the initial meeting and to subsequent meetings (see elaboration in Section V).

#### **\*Sets tone & keeps it positive**

The facilitator is responsible for modeling a positive, upbeat approach. The tone of meetings should be set in the spirit of fun. Serious issues will come up, but it is important to try to refocus the group if the energy becomes negative or pessimistic.

#### **\*Establishes norm of equality among group members**

Most relationships within public school settings are hierarchical, and students are conditioned to view the adults in the environment as authority figures who generally have the final word. Facilitating friendships requires a break down of this traditional power structure. Around the Building Friendships table; peers, teachers, parents, and others all operate from a place of equality and

equal voice. There is no 'authority figure' in the typical sense. Students are encouraged to speak up. After all, the development of peer relationships are critical to the success of the building friendships process. Students need to help shape and determine the group outcomes. To the greatest extent possible, the student with the injury, is encouraged to make suggestions and decisions. The student for whom the building friendships process was implemented has final approval for all ideas generated by the group.

**\*Provides motivation & cohesion - guides/monitors**

The facilitator is the backbone of group development. The facilitator needs to track, guide, and at times contain the dynamics of the group and the individuals within it. While this task sounds daunting, keeping track of all these elements becomes second nature with a little experience.

**\*Is willing to stretch status quo & experiment**

A good facilitator will encourage group members to risk trying new ideas. Social situations are often static, and people can spin wheels problem solving. Creative risk-taking is when someone stands up and suggests something previously not considered or something thought of as impossible.

**\*Builds a sense of community - makes things engaging**

There is nothing quite as heartwarming as realizing the moment when a group suddenly *feels* like a group. Camaraderie among group members is present, and an underlying feeling of support for one another emerges. This is the moment you've been waiting for. From this time on, the development of deeper relationships among group members become possible. Groups have long been studied, and there are many activities which help group members feel more comfortable with one another. A verbal "check-in" is often used to help people get to know one another. In some settings, a "warm-up" activity might be used to help with this process. Activities can be structured (e.g., bring and share baby photos, have a talent contest), informal (e.g., hanging out at a favorite coffee shop or mall) or planned (pizza, swimming, bowling).

One of the most important considerations is that for activities to be fun and reinforcing, they must be of high interest to peers. Keep activities light, fun, and interesting.

### How to Get Started as a Facilitator

- Make a conscious decision to devote time & energy toward improving the social life of a particular student or group of students
- Present your facilitation proposal to the appropriate supervisor
- Gain administrative support & permission from home & school (see samples of letters to parents/peers)
- Read other accounts of facilitation (see references section)
- Talk to others who have been involved in group processes
- Start organizing your group!!
- Have fun!!

### What a Facilitator Is Not

While embarking upon the journey of facilitation is exciting work, there are some cautions to be aware of. It is important to understand and come to terms with where your role as a facilitator ends, and to be aware of those moments when you are feeling pulled or asked to cross that line. The same parents and educators who brain stormed the list of facilitator functions also devised the following list which represents some of what a facilitator *is not* responsible for.

A Facilitator is Not:



- \*A savior
- \*A social worker
- \*All-knowing
- \*Teacher
- \*Academic advisor
- \*Forever
- \*Hopeless

- \*Inflexible, static, rigid
- \*Risk averse
- \*Controlling
- \*Perfect
- \*Stodgy
- \*Authoritarian
- \*Discouraging

## Who Should Facilitate? Mixing Other Roles with That of Facilitator

There are advantages to being connected with the particular school one seeks to facilitate in. For one thing, you know other school personnel and the physical layout of the building. You probably have a good idea of the types and variety of classes as well as extracurricular activities that are available. You have a good sense of the student body, their attitudes, values, and behaviors. You may have spent time with the student who sustained an injury prior to the time of the injury. You may have a sense of where the student was headed, his/her goals, social group, and family.

## **Section III:** **History of MAPS & Circle of Friends**

Since the Building Friendships process incorporates both the Maps and Circle of Friends support-building strategies, this section will summarize the approaches used in both Maps and Circle of Friends. The Building Friendships process will be explained in detail in Section IV.

### History of MAPS

Originally conceived in the 1980's by a group of educators, "MAPS" used to be an acronym which stood for the Mcgill Action Planning System, and then for Making Action Plans. Today, "MAPS" is not an acronym (see Appendices for article). MAPS simply describes a framework for facilitating the full inclusion of students who have disabilities. The MAPS framework is excellent in that it provides a general process and direction for 1) bringing together a group of people, and for 2) problem solving on behalf of individuals who are in need of support.

### The Original Intention of MAPS

MAPS was developed with four specific guidelines for implementation. Those who created MAPS held the belief that the process would only work if the following conditions were met:

- answer all the questions of the MAPS, although the order can be adjusted based on individual and group dynamics
- have a person who records responses to questions using graphics
- have two people co-facilitate MAPS
- go through MAPS oneself before attempting to lead others through the process

### The Eight Key Questions of MAPS

There are eight key questions which form the current foundation of the MAPS framework. The role of the group members



are to answer these eight questions, as a group. This process helps the group focus on the life issues of the individual in need of support, in order to develop and take action on an individualized plan. The following are the eight key questions asked in facilitating a MAPS:

1. What is a map?
2. What is the story?
3. What is your dream?
4. What is my/our nightmare?
5. Who is the student?
6. What are the student's strengths, talents, & unique gifts?
7. What does the student need?
8. What is the plan of action to avoid the nightmare and make the dream come true?

### Circle of Friends

Circle of Friends is a concept which was created in order to develop a cohesive group around a socially isolated peer. Ideally it can be used as a system for setting up a network of mutually interdependent individuals, but in its original incarnation it was designed as a support for one person. A graphic was created in order to provide a visual representation of an individual's current social system. This graphic is discussed in Section IV.

## **Section IV:**

### **Steps of the Building Friendships Process**

The Building Friendships Process is a variation of MAPS and Circle of Friends. In the literature on social relationships there is a distinction made between social and emotional isolation. The Building Friendships process can effectively address issues of social isolation by connecting isolated students with peers through various activities. However, the emotional isolation which often accompanies TBI generally takes a long time to mend. A process which only can only occur through the development of a close friendship.

#### What makes Building Friendships work

While in some ways Building Friendships has been condensed for the sake of utility, in many ways it offers a more detailed approach to facilitating social relationships. The original MAPS meeting was designed to last at least three hours. The initial meeting in the Building Friendships process can be conducted in one to one and a half hours or less. The follow-up aspect of the Building Friendships process is more extensive than the MAPS. However, any of us who have tried to facilitate change know that the quality of follow-up often makes or breaks a successful transition.

#### Who is served by the Building Friendships process

The Building Friendships process should be as student-driven as possible. The social well-being of the student is of utmost importance, and regardless of communication, physical, or behavioral difficulties, the student needs to be given every opportunity to direct his/her own future. This process empowers not only the student with the injury, but everyone who participates. Through the steps that will be described below, the group arrives at goals to work toward, and develops an action plan in order to meet those goals. The four steps or phases in the Building Friendships process are presented below, and provide a general "script" for the first meeting.

**Phase I. Gathering information.** It is important to get as much up front information as possible about the student and the student's current social situation.

- Interviews with the student, family members, peers, and teachers will help determine what the current social needs are.
- Begin to identify opportunities for increasing the students' social experience within the school setting (e.g. what do other students do on breaks? Before and after school? At lunch time? Are there clubs to join? Can a club be started?)

Gaining an understanding about the student and the student's current situation will save time during the initial meeting that might otherwise be spent on background information, and will be a benefit in figuring out who to invite to the first meeting.

**Phase II. Recruiting participants.** Based on interviews held in phase #1, you will make some discoveries about what people are instrumental in the student's life. There are no set rules for who to invite to the first or subsequent meetings. The objective is to:

- develop a core group of individuals (e.g., peers) who are willing to commit to participating in the Building Friendships process.

For suggestions about recruitment please refer to section V.

**Phase III. Conducting the initial meeting.** The purpose of the first meeting is to:

- share information about the student and his/her current social situation, and
- to create a vision for the future.

**Phase IV. Holding regular review meetings.** Review meetings are scheduled in order to:

- discuss progress toward achieving the goals.
- revise plans and strategies if necessary, and
- reevaluate group membership.

### What You Will Need for the First Meeting

1. Flip chart stand and paper
2. Colored markers
3. Snacks & drinks
4. Decorations (balloons, flowers, party favors, etc.) that may contribute to creating a pleasant atmosphere

### Other Things You Need to Know

1. **Graphics.** The visual aspect of the meeting is very important. Everything should be recorded on the flip chart paper as neatly and as colorfully as possible. Often family members want to keep some of the sheets. Little drawings add to the overall power of these visual representations. Sometimes someone in the group, including the student with TBI or a peer, wants to help with the recording of responses.
2. Not all students will be able to speak for themselves. But it is critical that each student is drawn into the process to their fullest capability.
3. The most important considerations are the wishes and feelings of the person being supported. Check in with the student frequently to make sure that decisions and ideas are acceptable to the student (this helps assure that adults are not solely directing the process).
4. Sometimes what a student or peer thinks is at odds with family members or teachers, and vice versa. This is okay! It is critical that all issues are treated with care and respect, and discussed until all members of the group accept a mutually-satisfying compromise (Sometimes specific issues need to be dropped, or put on hold to be returned to at a later point).

**Students who are being supported need to trust that nothing will be done on their behalf that does not feel right, and that their voices have meaning and power.**

### Agenda for The Initial Meeting

The first meeting is not only the most structured, it is the most important. It is a time for bringing together a group of people in support of a student, and a time for paving the way for things to come. Taking polaroids or collecting photographs of group members at the first meeting is a good way to establish rapport.

The format described here helps to provide a solid foundation for the Building Friendships process. It is amazing to see what a group of like-minded people can generate in a short amount of time. The steps in this process are logical, and if followed, really contribute to the vision group participants have for the student's future. It is important to remember that since each situation is unique, there is no way to predict the outcomes of the first or subsequent meetings. As such, we have provided general suggestions on the sequence of future meetings.

Each of the following steps for the first meeting will be explained below.

- 1.) Introductions/Overview
- 2.) Why we are here: Clarification of Values
- 3.) Who is the Student?
- 4.) Circle of Friends
- 5.) Hopes & Dreams
- 6.) Targeting & Prioritizing Goals
- 7.) Fears & Obstacles to Achieving Goals
- 8.) Identifying Strategies to Overcoming Obstacles
- 9.) Action Plan
- 10.) Closure

## **STEP #1: Introductions/Overview of Meeting**

- **Establishing a sense of equality among group members is important.** Ideally the adults and peers who come to the first meeting should understand that they are there as people who are in support of a particular student. This creates a different tone than having people come in their professional roles and identities. **At a Building Friendships meeting everyone should feel as though they are on equal ground.**
- **The facilitator provides a brief, general overview of what the group can expect for the first meeting.** This includes an idea of how long the meeting is anticipated to last, and a statement concerning the hoped-for outcome, which will be a plan for increasing social activity for the student which will be generated by the group. It also is important to make a statement about the commitment that is necessary in order for the group to achieve the goals they will develop. **Group members should know that by the end of the first meeting they will be asked to what degree they feel able to commit to the Building Friendships process.**
- **Participants are asked to introduce themselves.** This is a good time to use a "warm-up" activity. Each person also can state their connection to the student.
- **The facilitator then defines what a map is.** It provides directions to find a place, but there are many paths which lead to it. Explain that the group which has gathered will be creating their own map, and traveling to their chosen destination together.
- **The facilitator needs to describe the process of brain storming.** It is most critical that participants understand that in brainstorming all answers are accepted and honored without judgement. It is okay to dream, to be 'unrealistic,' to be creative and in the moment, and to provide stream-of-consciousness suggestions. All of these elements help to generate ideas which may seem new and daring and bold. Good! It is just those kinds of suggestions which help make this process work!

## **STEP #2: Why We Are Here: Clarification of Values**

- **The facilitator is responsible for creating a safe, relaxed feeling.** An 'icebreaker' question or warm-up activity is a good way to dispel tensions, and to create an atmosphere of informality.
- **Asking the group to brain storm** about the nature of friendships, and the effects that friendships or the lack of them have in our lives, **is a very effective way to find a common ground among group members.** Record responses and ideas on the flip chart. As each chart is created, it should be posted in the meeting room. In this way, all participants can see and track each chart. Each chart is an integral part of the map.

**The facilitator summarizes** the importance of friendships for maintaining personal happiness and well-being, and that for some people, support is necessary in order to establish a satisfying social life.

### Sample Questions (more than one can be asked):

- Why are you here today?
- How do you know the student?
- What is friendship to you?
- What would life be like without friends?
- What are some things people like to do with friends?

### Sample Activities:

- Blow bubbles at one another
- Talk to a person in the group whom you do not know well, and tell him/her three important things about yourself
- See if you can make the person across from you laugh
- Eat a special snack together

## **STEP #3: Who is the Student?**

- **The facilitator asks the group to think about all the positive, wonderful characteristics and attributes of the student with TBI.** Identify the special things that everyone knows and loves about the person. What are the person's strengths, gifts, and abilities?

Record member's responses on a sheet with the heading "WHO IS (name of student)?" Use lots of colors, stars, stickers for this chart.

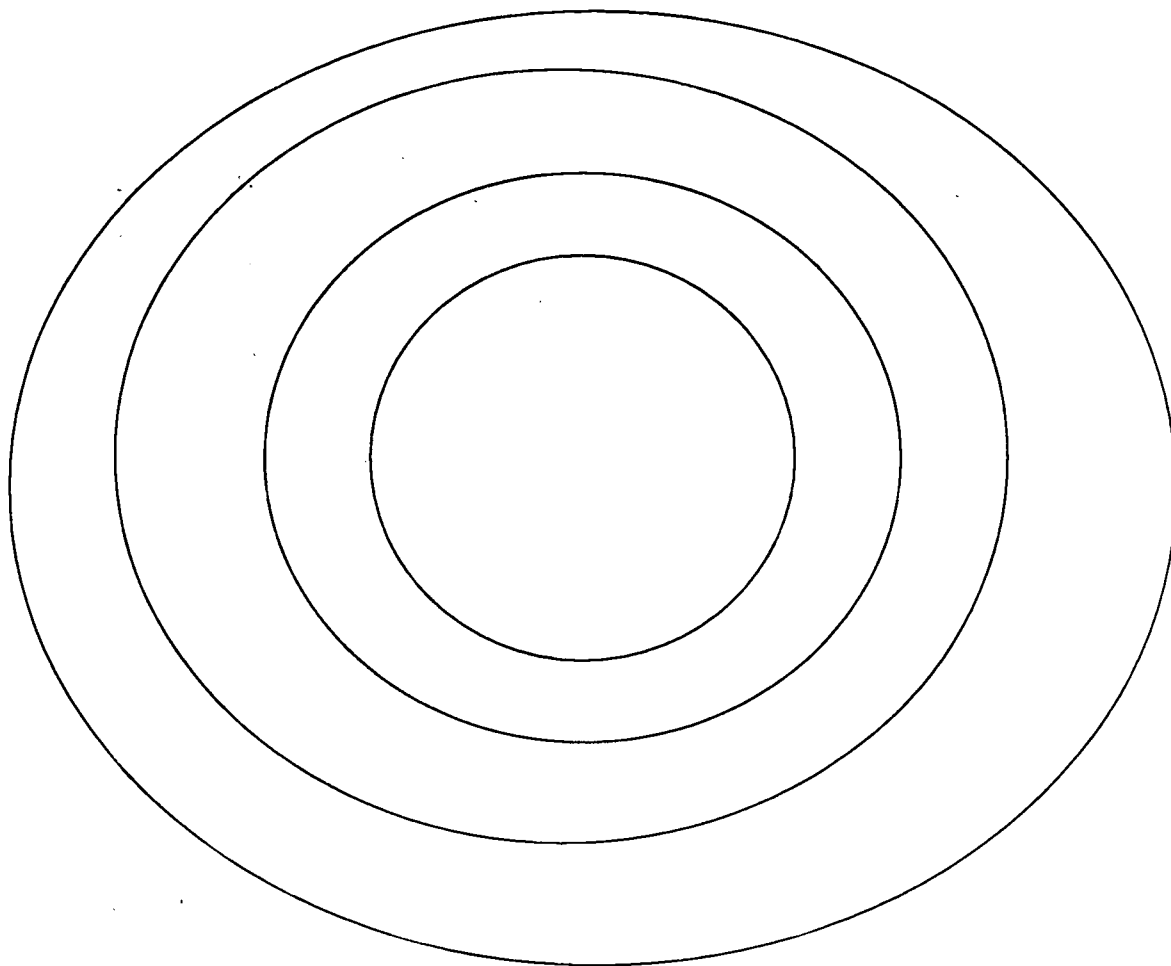
- **The facilitator needs to make sure the group stays focused on positive aspects of the student with the injury.** This step can have a profound affect on family members, and can be very emotional. It is not unusual to find that this is often the first time parents have heard their child referred to in such a positive light. For the student with TBI this can be an extremely important moment which can greatly enhance self-perception. **Giving this sheet to the student at the end of the meeting can be a great gift.**

#### **STEP #4: Circle of Friends**

- This step visually represents the student's current social situation. Based on information gathered prior to the meeting, the circle can be completed before the meeting. This not only saves some time, but helps group members immediately grasp the necessity of supporting the student in developing a richer social life.
- The student's "circle of friends" is visually displayed using four nested rings. Each ring represents how close the student feels to each person who is part of his/her current social situation. The innermost ring, is for those whom the student feels closest to. The outermost ring is for those with whom the student interacts, but does not consider to be a "friend" (e.g., paid service provider; sibling).
- Now is the time to ask the student, and then others, if the people identified in each circle accurately represent the level of friendship. If the circle was created before the meeting is not quite representative, it can be modified at this time. Using colored "post-its" for the initial map makes it quite easy to make changes.
- This step can be very sensitive, and the facilitator needs to pay attention to what group members are feeling. Sometimes the student will place paid service providers in the very inner circle, while the student may not perceive family members to be as close. Other times, someone who is quite important to the student might be left off the circle map entirely.



- Possibly nothing is more important than this step. Seeing the reality of the student's current circle of friends clearly identifies where the work in social facilitation needs to occur. Sometimes a student who is particularly isolated will have no one listed in the categories of close, trusted friends, or acquaintances. The overall goal of the Building Friendships process is to bring those peers listed in the outer circles closer to the student, and eventually to be able to add names to the circles where none before had existed.



## STEP #5: Hopes & Dreams

- This meeting is the time to begin painting a picture of what the ideal social situation looks like for the student. List all the Hopes and Dreams that each participant has on a chart. Always start with the student's own hopes and dreams, and check in frequently with the student to make sure that he/she agrees with the hopes and dreams expressed by other group members. As we have stated, the Building Friendships process is student directed. There is no point in trying to achieve a goal that the student has no interest in.
- If some hopes and dreams seem unrealistic for the student, that is quite alright. Realistic options often come from ideals. Sometimes people are afraid to list things which are impossible (e.g., such as a student with very little motor control and limited speech becoming a physician). Often there are other ways this type of hope and dream can be achieved, but those other possibilities would never present themselves unless the hopes and dreams are out in the open.
- At this stage the facilitator may need to redirect the group back to focusing on the student's social situation, as often hopes and dreams can extend to many realms. It is important for the facilitator to bring the discussion back to social needs and goals.

## STEP #6: Identifying & Prioritizing Goals

- This step is often the most difficult for facilitators. Based on the hopes and dreams, it is now time to identify concrete goals and steps which will make achieving the hopes and dreams possible. For instance, if having more friends was a hope and dream, it might need to be narrowed down a bit more in order to frame it as a goal. The goal, therefore, might become "to have more friends in school." By looking at the list of hopes and dreams, the group needs to decide what ones seem the most important at the moment. Sometimes it is best to start with one or two goals. Definitely no more than three immediate goals should be identified.

- After the main goal or goals are identified, they must be prioritized. During this process sometimes it becomes obvious that achieving one goal actually would cause the other goals to fall into place. It is up to the facilitator to look at the logical sequence of things, and to maintain an order that seems to make the most sense.
- It is important that group members realize that the other hopes and dreams and goals are not being ignored, but that they are being put on hold for the time being, to be returned to at a later date.

### **STEP #7: Fears & Obstacles to Achieving Goals**

- This step is a time to look at the prioritized goals one at a time, and determine what stands in the way of the goal. So, for instance, if the goal is to have more friends in school, all the obstacles to this are listed under the goal.

### **STEP #8: Strategies to Overcome Obstacles**

- Once the obstacles are identified, the group uses its creative, brainstorming energy to come up with strategies which will overcome the obstacles. Remind the group that there are no "wrong" solutions.
- It might become apparent that there are many obstacles under a particular goal, and that the strategies are time consuming and difficult to achieve. The facilitator might make a decision to stick with just this one goal for the time being, rather than trying to proceed to cover all the chosen goals.

#### Some Strategies to Consider

- \*Schedule changes to promote increased contact
- \*Lunch clubs
- \*Peer education about TBI, Inclusion
- \*Peer initiation training
- \*Organized recreational activities
- \*Cooperative learning activities
- \*Peer tutors, Buddy systems
- \*Friendship programs

## **STEP #9: Action Plan**

- Once all the strategies are listed, it is time to create an Action Plan. The Action Plan consists of three columns: Who/What/By When.
- The facilitator asks for volunteers to take on the various strategies, and names are filled into the chart accordingly. It is important to designate a time frame for when these strategies are expected to be achieved.

## **STEP #10: Closure**

- The facilitator needs to summarize the events of the meeting, and to review where the group is in its process. Time and participation should be acknowledged. It also can be a time for any members of the group to offer feedback or to comment on how the meeting went, or any special meaning it had.
- Before everyone disbands, the next meeting date should be identified. The facilitator also lets participants know that if they feel unable to make a commitment to the Building Friendships process, it is important that they discuss it with the facilitator privately or in the context of the group.
- If the group decided that they want notes from meetings, it is the facilitator's responsible for distributing notes. Getting into the habit of sending out meeting summary notes helps maintain continuity, and contributes to group rapport. It is very important that the facilitator keep open communication and contact with group members between meetings, and to take time to do some brainstorming with any individual who is having difficulty following through on the Action Plan.

## The Follow-up Meetings

### **STEP #1: Overview**

Provide a brief introduction to what will occur at today's meeting & what the desired outcome is.

### **STEP #2: Review previous goals**

Go over goals from the last meeting, and check-in with each member of the group to find out what progress has been made, what has been accomplished, and identify any areas where the process seems stuck. If a particular goal is being extremely difficult, and group members are feeling stuck and frustrated, it sometimes makes sense to put that goal on hold for awhile, and move on to a new goal. This is preferable to staying stuck and frustrated. It is possible that the goal is unrealistic, that other steps need to happen first, or it may be a goal that can be returned to at a later time. It is important to make movement and to have moments of feeling 'successful.' It is okay to throw out goals that aren't working, and replace them with ones which are.

### **STEP #3: Update on Action Plan**

It is a good idea to review and update the action plan at each meeting. This creates continuity and structure and holds group members accountable to their commitments.

### **STEP #4: Feedback from group**

Keep in mind that each member of the group needs to feel honored and heard. If there are issues or concerns, the group should be a safe place for people to voice their opinions and feelings without fear of being reprimanded. This type of open communication will make for the best, most productive groups with the most solid core members. The strongest groups are those in which members feel that they are in control of the process, and can have a say in altering that process if changes are deemed necessary.

### **STEP #5: Closure**

It is always important to close each gathering of the group by providing a summary of the latest changes, decisions, etc. Any positive outcomes, no matter how slight, should always receive acknowledgement and be celebrated. Group morale is important,

and closing each meeting on a positive note helps keep the group going, especially through challenging times.

## Section V: Recruiting Participants

Aside from skillful facilitation, recruiting people to participate in the Building Friendships process is the most important aspect to consider. As with the rest of the process, there is no 'right' way to go about the task of recruitment. These are some suggestions that have worked best in our experiences.

Many questions about recruitment come up for prospective facilitators: Who should be invited to the first meeting? How do I approach people? What exactly do I tell them about the purpose for coming together? How much information should I give peers about the student with TBI? Do I talk about the student's disabilities?

There can be stress associated with organizing for this first meeting: The student may fear that no one will want to participate. The family may never have been involved in a process of this type. Teachers and others may wonder how much of their time and energy will be expected. Peers may fear that they will be asked to be 'best friends' with the student being supported, and the facilitator, who is the backbone of the entire process, may wonder how on earth to pull the whole thing together.

All of these doubts and apprehensions are entirely natural, and it is important to keep this in mind. After the initial meeting a great deal of stress and pressure is alleviated as everyone involved gains a sense of what to expect.

### Who to Invite

There is no set standard for who to invite to participate. Sometimes there are two or three people at the first meeting, and sometimes there are thirty. The ultimate goal, however, is to create and establish a strong core group. In the best of circumstances, this core group will remain the one constant throughout the life of the Building Friendships process. Others may come and go as needed,

or have sporadic attendance and involvement. But the core group, hopeful, will be committed in the long term.

Usually the core group is made up of the student with TBI, the facilitator, one or more family members, and several dedicated peers. In some cases no peers have been identified as potential group members by the time the initial meeting is to occur. This is okay. It is not essential to have peers at the first meeting, but it is preferable. Some facilitators who begin groups without peers later state that if they had to do it over again, they would strive to include peers much earlier on in the process.

For the first meeting is is a good idea to look at who the most important people are in the student's current life. Often the following people come to mind:

- \*Family members, including extended family (parents, siblings, cousins, grandparents, aunts & uncles, etc.)
- \*Friends & acquaintances
- \*Teachers & other professionals
- \*Other members of the community

### How to Invite Them

Invitation to the first meeting can be done very informally through word of mouth, or more formally through written notices. Much of the approach for actual invitation will depend on the facilitator's relationship with the people involved. If relationships already are established with family, teachers, and peers the facilitator's job becomes much easier. In some cases facilitators have to actively seek participants. The following are some ideas for inviting people to participate in the Building Friendships process.

When there are obvious people to invite:

- \* Ask the student with TBI who should be invited
- \* Ask the family who they think is important to invite

\*Talk directly to people whose presence seems important

When the student is extremely isolated it may be necessary to:

- \*Talk to one peer and have that person talk to others
- \* Make a presentation to specific classes
- \* Enlist the support of a teacher or other staff person for suggestions
- \* Post notices in strategic places around school
- \* Place an announcement in the school newspaper
- \* Approach classes where projects and community service are required

Some of the above suggestions are more appropriate for older students who tend to be more isolated than those in elementary school. The more personal approaches are always preferred, just as it is preferred to involve peers and others who really want to participate, but sometimes it is necessary to seek participants who may receive credit for involvement.

### What Approach to Use

There are several ways to explain the intention of the forming group to prospective participants. The traditional MAPS process has one individual as a focus whom others are asked to support. Soemtimes, however, this approach in itself can create further isolation by singling out one person to receive attention. In some instances it is preferable to create a situation which has as its focus the whole group, and the student with TBI is a part of the group. This approach can be more natural, yet just as challenging.

If a whole group approach is taken, it can be framed as a friendship group for everyone. In this case, the steps of the Building Friendships process listed previously have to be modified to fit a whole group situation.

If a focus on the one student is taken, there are a number of approaches which can be used in order to explain the purpose of the group to others. the most straightforward approach usually is to



state that the intention of the group forming is to give support to a student who would like more social opportunities.

Whether or not to discuss a student's disabilities upfront is a question which comes up often for facilitators. Again, there is no 'answer' to this question, but only suggestions. The pros and cons of providing information about a person's disability need to be weighed in each situation. Some believe that it is best to wait until some sort of rapport has been established before raising issues associated with a disability. Others believe that rapport is not possible to achieve without first providing information.

If the student with TBI is able to communicate verbally, and is comfortable with the process, sharing the experience of injury and recovery can have a profound affect on increasing understanding among peers. Sometimes parents also are willing to participate in providing a presentation with a question and answer period for peers. Often this sharing of this kind can serve to dispell fear of the unknown, and can provide a safe place for peers to ask difficult questions.

In other cases, however, groups can organize around a person with a disability, and while that disability rarely, if ever, is discussed, group members constantly are engaged in a process of getting to know one another as individuals, without having to single out someone on the basis of a disability.

**Section VI:**  
**Benefits: What the Kids Have to Say**

Middle school students who were intensively involved in an inclusive social group for one year had the following suggestions when asked what it is they believe makes it possible for diverse people to come together in meaningful ways:

**\*Create a context for community:** This is necessary so that people can feel that they belong somewhere, and can feel connected - the focus is not just for one person's benefit, but benefits all

**\*Keep in touch with each other and find things you have in common with one another:** This creates stronger, deeper ties

**\*Realize that somethings people can work to change, and other things are just a part of that person:** This can be a fine line, but should be walked at all times. We all have parts of us that we can work on improving, but some things we just have to accept about one another. That's what makes us unique.

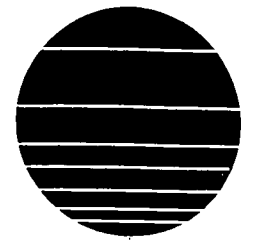
**\*You don't always have to love everyone:** people can be a valued and fully included as part of the same community and be treated with kindness and respect without being best friends or even loving one another.

**\*Work together toward the common good:** People in a group together who are working toward a purpose outside the group can develop even closer bonds

**\*Find ways to have a lot of fun together:** Stay close to what is is that kids find fun and engaging and do lots of it!!

**APPENDIX C: TBI UPDATE NEWSLETTERS**

# TBI UPDATE



JUNE, 1995 Teaching Research - Eugene

## What's Happening with the TBI Inservice Teams

The Central Oregon, Columbia, and Southern Oregon teams are up and running in their respective regions! Since this fall, the **Central Oregon team** has been working closely with St. Charles Hospital to provide a smooth transition for students returning to school. Five students in the region were injured over the summer months. *Kathi Fielder*, School Psychologist, and *Amber Turnage*, Regional Nurse, were integrally involved with discharge planning, IEP development, and school consultation activities for several of the students. Last fall, team members organized a regional inservice on pediatric brain injury. Over 15 participants attended the all-day workshop co-sponsored with St. Charles Hospital, which

focused on the physical, cognitive, behavioral, and social effects of TBI.

Although they have just recently completed their first series of trainings, **Southern Oregon team** members have already begun publicizing their availability. They are working closely with Regional Coordinator, *Lew Keller*, to let districts know they can provide consultation and inservices for schools serving students with TBI. The teams' efforts have been productive; *Margay Garrity*, Regional Nurse, who serves as the team's liaison, has been receiving numerous calls from interested districts. The team has worked hard to recruit members throughout their region, and they are now ready to assist students, families, and educators in all areas in Southern Oregon.

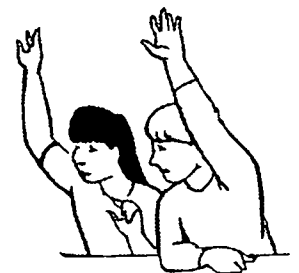
Several members of the **Columbia team** are preparing for a regional Supported Education Conference to be held on June 26 and 27 in Portland. *Gay Bauman*, Multnomah ESD Coordinator, *Jane Fielding*, Special Ed. Consultant, *Gene Morrill*, School Psychologist, *Joann Muller*, Special Needs RN, *Kitty Phillips*, Speech/Language Pathologist, *Kathy Shannon*, Education Specialist, and *Carol Wong*, Education Evaluation Specialist, have been meeting regularly to plan a poster session for the conference. *Kay Sample*, teacher and team liaison, has been providing consultation to a number of districts requesting assistance. Unfortunately, Kay will be leaving the team in August when she and her family move to northeast Washington. As both a professional and a parent of a child with TBI, Kay has offered a unique perspective in how to best serve students with TBI. Good luck Kay — we'll miss you! ●

## News Update!

Central Oregon Team Liaison *Amber Turnage, RN*, was named the 1995 Nurse of the Year by the Oregon School Nurses Association. After working with Amber for the past 2 years, members of the Central Oregon team can understand why Amber received this award: she is hard-working, dedicated, and extremely thorough in her work. Congratulations Amber!

## INSIDE THIS ISSUE:

Families and Students Get Caught	2
Teaching Research Staff Profiles	3
Building Friendships:	4
UPDATE: Qualitative Longitudinal Study	5
Upcoming Trainings	5
Myths and Facts about Childhood Brain Injuries	5
Resources	6



## Families and Students Get Caught Between Medical and Educational Systems

by Marilyn Lash, MSW

The incentives and resources of educational and medical systems may impede the critical collaboration and programming that are needed for a child's reentry to school after a brain injury. Differences in authority, service delivery, regulation, and funding affect the child's transition from hospital to school; families often get caught in the middle.

### Who's in charge?

The person traditionally in charge of the hospitalized child is the physician who also controls admissions. Physicians have the option of electing or denying admission based on the child's

### It is the parent who must approve the educational plan...

clinical needs and goals for rehabilitation. Insurance coverage can also be a factor. By contrast, schools have no choice about providing education. It is mandated by law; every child is entitled to an education. What is negotiable is *how and where* the child will be educated. Although traumatic brain injury was recognized by the Individuals with Disabilities Education Act (P.L. 101-476) as a condition resulting in special needs, entry into the special education system can be a lengthy and complex process. Unlike the medical setting where the physician is in charge, it is the parent who holds the final authority and must approve the educational plan for the student.

### Monitoring progress

The in-patient rehabilitation team sets goals and documents progress via the medical record which is monitored by the hospital's utilization review committee to justify the level of

hospital care required for payment. Length of stay is largely based on clinical factors. If progress is too slow, the child's stay may be extended or the child may be discharged to a less intensive level of care or home. If progress is more rapid, the discharge date may be moved up.

Schools monitor a student's progress by the goals and objectives in the educational plan. However, the school can not "discharge" a student if progress is too slow. Goals need to be revised, services renegotiated, and educational plans rewritten. Final approval still rests with the parent(s).

### Where are the resources?

The typical in-patient rehabilitation team includes a psychiatrist, neuropsychologist, rehabilitation nurse, physical therapist, occupational therapist, speech and language pathologist, social worker, recreational therapist, and vocational counselor. The intensity and range of services changes with the patient's recovery. Some facilities have specialized pediatric brain injury teams for consistent and comprehensive treatment.

By contrast, the majority of students in local schools are not health impaired. Staffing of special educators and allied health professionals in schools varies by the number of students needing special educational services. With a multi diagnostic population of students with special needs and limited staff, few schools can develop specialized brain injury teams.

### Who pays?

Rehabilitation hospitals are at an enormous advantage compared to schools in negotiating and recouping the costs of their clinical services. Hospital per diem rates factor in basic operating

costs; specialized services are usually billed separately. Rehabilitation providers can spread their costs over a patient base and project needed occupancy rates for fiscal solvency.

By contrast, schools operate on annualized school budgets that are based on formulas of local, state and federal dollars. Most schools do not have large groups of students with brain injuries to share resources and spread costs as do hospital programs. The entry or return to school of a student with a brain injury can create a fiscal crisis for the school.

### Building partnerships

Below are suggestions for linking medical/rehabilitation and educational systems.

- Education is a two-way street. Many health/rehabilitation professionals conduct in-services for local schools or present at conferences on the effects of traumatic brain injury. Medical staff need to learn from educators about the options, resources and limits of special education.
- Reimbursement for school based consultation. Mechanisms to pay for on-site consultation by rehabilitation providers with school staff are needed. Otherwise, gains



achieved at great expense during in-patient stays can be quickly compromised.

- Parents need more information about community based services.

Many community programs for children with special health care needs offer training for parents in advocacy and special education. Parents of children with brain injuries need to be informed of these resources even though they are not specific to brain injury.

- Parents need training to become their child's service coordinator.

Professional case managers need to educate families about the *process* of service planning and evaluation rather than simply delivering the care plan. Families can become empowered to take on the responsibility and learn the necessary information and techniques for planning for their child's future needs.

### Summary

Health care providers and educators share the common goal of maximizing a child's potential for rehabilitation. Rather than continuing to allow the special interests of payers, hospitals, and schools to restrict the choices and services that are available, mechanisms need to be developed so that they complement each other. Only then can comprehensive and cost effective rehabilitation and education be designed and provided for children who have had traumatic brain injuries.

*Note: This article originally appeared in the Summer/Fall 1994 issue of REHAB Update. The entire article is available at no charge from the Research and Training Center on Rehabilitation and Childhood Trauma, New England Medical Center, 750 Washington St., #75K-R, Boston, MA 02111 (Attn: Publications Coordinator).*

## Federal Definition of TBI

Federal Register, V. 57, No. 189 (9/29/92)

"Traumatic Brain Injury" means an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

## Teaching Research Staff Profiles

In this volume of TBI Update, we thought we'd introduce you to the TR staff. As you'll read, we come from a variety of backgrounds...

**Bonnie Todis, Ph.D.** has over 20 years of experience as both a teacher and researcher in special education. The focus of Bonnie's research activities has been promoting the social integration and self-determination of students and adults with disabilities. Bonnie feels that it is critical to understand the perspectives of those we are trying to serve in order to design programs and interventions that will meet their needs. In order to access these perspectives, our work group at TR incorporates a qualitative research component into our projects whenever possible. On the TBI Inservice project, Bonnie focuses primarily on our longitudinal qualitative study of 5 students with TBI.

For the past ten years, **Ann Glang, Ph.D.** has worked as a field researcher in a variety of areas related to service provision for youth with TBI: home/school support services for families, school consultation, social integration, and instructional interventions. The TBI Inservice project is the third project she has

directed focusing on pediatric TBI funded by the U.S. Office of Special Education. Prior to pursuing her research interests, Ann worked as a psychometrist/behavioral consultant in an inpatient rehabilitation unit and as a teacher trainer at the University of Oregon. One of Ann's skills, and areas of interest, is "diagnosing" problems in academic instruction and helping teachers adapt instruction to meet the needs of students with special needs.

Since 1980, **Larry Irvin, Ph.D.** has served as a Principal Investigator for many federally-funded projects. A nationally recognized expert in assessment and evaluation, Larry consults throughout the country with programs focusing on families and schools. On the TBI Inservice Project, Larry helps design and coordinate evaluation activities.

Project Coordinator **Tuck Stevens** has worked in educational research for over 25 years. She has a vast amount of experience in coordinating research and data collection activities. Tuck is the key contact person on the TBI Inservice Project for team members needing materials or assistance in their consultation and team activities.

## Building Friendships: A School-Wide Effort to Expand Joey's Social Network

Joey was a second grader when he became involved in the Building Friendships Project at Teaching Research-Eugene. Joey was injured in a motor vehicle accident when he was three years old. As a result, he experienced significant expressive language difficulties and severe behavior problems marked by low frustration tolerance and frequent temper outbursts. Before his involvement in the Building Friendships project, Joey was extremely disruptive in the school setting, even with a one-on-one aide. Children were afraid of him, as were many adults.

MeriLe Glass, the special education teacher who became Joey's Friendship Facilitator, took over his case coordination. She strived to create a sense of security in Joey by making expectations and guidelines clear, and by

**MeriLe realized that Joey "hadn't a clue" what one does with friends.**

following through with consequences in a consistent manner. Most of all, she made her classroom a safe and warm place -

a place where children wanted to be. Joey readily bonded with MeriLe, and his behavior began to improve dramatically.

Because of her interest in helping to create a social network for Joey, MeriLe was chosen to participate in the Building Friendships project as a friendship facilitator. MeriLe was fortunate to come from a school where she had full support

from the principal in her efforts to implement something new, and a general feeling of teamwork and camaraderie existed between MeriLe and other members of the school staff.

MeriLe brought together a team of people around Joey: his parents, his aunt, the second grade teacher in whose class Joey was spending increasing amounts of time, several peers who expressed interest in getting to know Joey better, and his one-on-one aide who was an instrumental person in Joey's school life. At the first meeting the team met to create direction and purpose for the team and to establish goals for increasing social opportunities. At this meeting MeriLe realized that Joey "hadn't a clue" what one does with friends. This was a poignant reminder of just how lonely and isolated Joey had become. A main goal decided upon that day was for Joey to have friends to play with at recess. The team brainstormed obstacles and strategies for making this happen, and an action plan was developed to help members of the team take the steps necessary to see this goal become a reality.

As the Building Friendships project continued, follow-up meetings occurred as needed to review and revise goals and action plans. The peer group also grew, and soon Joey could be observed on the playground, surrounded by children engaged in typical recess activities. Gradually the focus of the group shifted away from exclusive attention to Joey. More peers became involved to talk about friendship issues, and to plan and hold school parties and a dance. A disability awareness experience was also set up which the whole school participated in.

At the end of the three months Joey and his team were planning some activities to occur outside of school such as an excursion to the

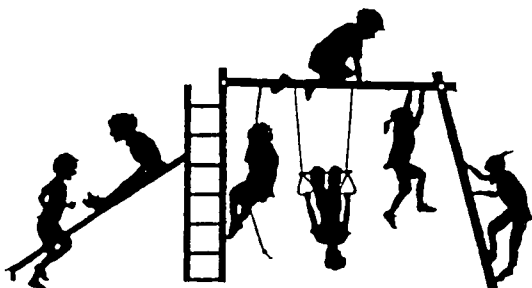
bowling alley. Joey was attending school for longer periods, and his aide was able to observe Joey from a distance instead of sitting by his side. While Joey still had times when he would be too rough with his peers, he was able to control himself to a greater degree, and temper outbursts occurred only on occasion. Teachers and students began to perceive Joey's strengths, and he was no longer feared. The principal remarked that as Joey's behavior got under control, his aptitude for school work began to shine through.

At last report on Joey's progress we were disheartened to learn that as many changes in his school



*Joey at school*

program occurred this academic year, he had regressed considerably. This serves to underscore the need for social support that is stable and long term. Facilitating social opportunities and relationships can make a tremendous difference in the lives of students who have experienced TBI, but ongoing effort is required in order to ensure that gains made will be maintained.



## Update: Qualitative Longitudinal Study

We have just completed the second of three years of our qualitative study of 5 students with TBI. The study involves informal observations of students in school settings and frequent informal interviews with teachers, parents, classmates, and the students themselves. Because our students range from preschool through high school, the longitudinal study helps point out challenges that face students, families and educators throughout the school career. Our initial data analysis indicates that four themes are apparent in the data from all 5 students:

**Context:** The conditions surrounding the school setting, and the school culture itself, have a tremendous impact on the type, extent, and quality of services that are made available to students with TBI. Some of the factors that influence context are lack of community awareness of TBI and shrinking school resources.

**Communication:** Collaboration among educators serving students with TBI is critical to student success, and open, respectful communication between home and school can be an asset. However, even in situations where parent/teacher communication is infrequent or difficult, students with TBI can be successful if educators and parents are mutually respectful. Because the needs of students with TBI are so diverse, educators sometimes feel thwarted if parents are not willing or able to implement behavioral or academic interventions at home. Our data show that students can make academic, behavioral, and social gains at school even if home conditions are less than ideal.

**Expectations:** A key to student school success is high, appropriate expectations. Students who are held to standards of behavior and academic performance that are

consistently challenging, yet within their reach, live up to the expectations that teachers have for them. Educators need to provide strategies, effective instructional techniques, consistent, appropriate feedback, and support for coping with frustration and mistakes.

**Building capacity:** Through our qualitative longitudinal study, we are able to study the effects of building educator and parent capacity through the Inservice Teams and other interventions. Our preliminary data analysis shows that increasing educator awareness of TBI issues through inservice presentations, consultation, and providing materials results in changes in the context, communication, and expectations surrounding the student with TBI. We look forward to studying the building of capacity during year 3 of the project, as all six teams provide services in their regions.

## Upcoming Trainings

New team members from Regions 1, 4, and 5 will participate in introductory trainings in August.

### Introduction to TBI

Region 1:

**August 10-11: Pendleton**

Regions 4, 5:

**August 23-24: Albany**

Team members who were unable to attend their team's initial training series are invited to attend either of these trainings. Contact Tuck Stevens (503-346-0597) to register.

A limited number of additional slots for interested persons who are not team members are available for a nominal fee.

## Injuries Among Children- Findings from the National Pediatric Trauma Registry

More than 20,000 children will die this year in the United States as a result of injuries. More than 30,000 children will have permanent disabilities as a result of injuries to the brain.

In their 1993 study of pediatric trauma in the U.S., the National Pediatric Trauma Registry reported that:

- Boys were injured about twice as often as girls.
- Children between 5-9 years were the largest group injured (29%).
- The vast majority of injuries occurred in the p.m. hours between noon and midnight when children are most likely to be out of the structured environment of school.
- Falls were the leading cause of injuries (26%).
- The next major mechanism was motor vehicle crashes with children as occupants (19%).
- The third leading mechanism was pedestrian injury (16%) where children are struck by motor vehicles.
- Close to 9% of the children were injured while bicycling.

Source: Research and Training Center in Rehabilitation and Childhood Trauma, Boston, MA.



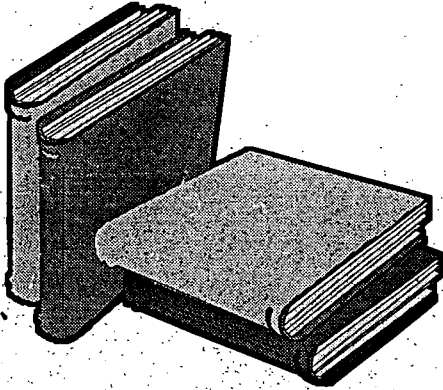
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Statewide TBI Services  
Lending Library  
Linn-Benton Educational Service District  
(503) 967-8822



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OHIF  
1118 Lancaster Dr. NE Suite 345  
Salem, OR 97301  
(503) 585-0855

Only 1 % of the 2,468 children admitted to trauma units after bicycling related injuries were wearing helmets (National Pediatric Trauma Registry, 1993)

Teaching Research - Eugene  
99 W. 10th Ave., Suite 337C  
Eugene, OR 97401  
Phone: (503) 346-0597  
FAX: (503) 346-0599

# UPDATE

October, 1994



TBI Inservice Project  
Building Friendships Project

Teaching Research - Eugene

## What's Happening with the TBI Inservice Teams

The Central Oregon TBI Inservice Team is working closely with St. Charles Hospital in Bend to ease the transition of students with TBI from rehabilitation to school. Central Oregon team members Kathi Fielder, Judy Newman, Veronica Russell, and Amber Turnage shared their team-building experiences and ideas for team activities with trainees for two new regional teams during a training workshop in Eugene, September 22-23.

The two new teams are the Columbia regional team, serving northern Oregon from Astoria to the Dalles and the Southern Oregon TBI Support Team, serving southwestern Oregon. The new teams will meet in their respective regions in November for continual training. Additional trainings are scheduled in January, March, and May. Team members will be available for consultation later in the school year.

The project will be training a new team from region V, the Mid-Oregon Regional Program representing Marion, Polk, Tillamook, and Yamill counties this winter. Like the other TBI Inservice teams, this team will include the parent of a student with TBI, a classroom teacher, special education teacher, instructional assistant, school counselor, school nurse, school psychologist, speech/language specialist, occupational therapist, physical therapist, and administrator. Educators and parents who are interested in serving on this team can contact Tuck Stevens at (503)346-0597 for more information and an application.



The final phase of the Building Friendships Project is now underway with plans to train one more group of school-based facilitators this fall. To date nine people in Oregon and Washington have been trained using the Building Friendships process, and have been able to facilitate an increase in social opportunities for students with TBI and other disabilities in their respective schools. Feedback to project staff from school personnel, families, and students concerning the efficacy of the Building Friendships process has been very positive.

A training manual and video presenting the Building Friendships process are being developed for publication and dissemination to school personnel, rehabilitation specialists, and others who are interested in alleviating social isolation for children and youth with TBI.

The following statements made by participants in the Building Friendships Project are indicative of what it has been like to be involved in this project (names have been changed to maintain confidentiality):

.....

*It's a real success story...I hope we can keep it going...we have found that David probably has a lot more ability to do academic work once we could control that behavior...I suspect he'll continue to gain as long as we keep this support group with him."*

- Principal

*"Kim just made a complete turn around. She knows how to communicate now... The meetings were extremely important. I was amazed at how much input we got from the kids. They were saying things that I was thinking but really couldn't say."*

- Parent

*"After we started this process David became a new kid...he doesn't have any behaviors that are really violent... kids come up and they want to play with David... He didn't have any friends before, everyone was afraid of him."*

- Teacher & Friendship Facilitator

*"I've really enjoyed being a part of this. I've learned a lot about friendships and kids with brain injuries, and the problems they go through...I think it's going to help me in future years working in Special Education."*

- Classroom Aide

.....

For more information about the Building Friendships Project, or if you would like to be notified when the manual and video package is published, contact: Judith Voss or Tuck Stevens, Project Coordinators, 503-346-0597.

## Current Educational Services for Students with TBI: The Parent Perspective

Despite the best efforts of school personnel, researchers and educators have identified a variety of challenges found by students with TBI as they reenter school. In an attempt to ascertain parents' perspectives of current educational services, a pilot survey and qualitative interviews were conducted during the 1993-94 school year.

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 other two parents had been injured more recently. 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 10 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.

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 improved communication between parents and teachers would in turn improve their child's educational program.

A series of qualitative interviews with a sample of parents provided further clarification of the problems they had encountered. As described by these 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. Following are representative comments made by parents which reflect each type of barrier to successful school experiences:

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

1 School does a poor job	3 School does a satisfactory job	5 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

• **Child's memory/organizational impairments:**

*One day he has all the assignments, but forgets the books he needs; the next day he has all the books but not the assignments. In grade school the teacher always told him what to write down and he did ok—this year he isn't writing down all the stuff he needs to get.*

• **Poor social integration:**

*The other kids were afraid of her because they didn't understand her problems.*

*The school didn't want him to come to the football games unless*

continued p. 3

## The Parent Perspective (cont'd)

*I accompanied him because they were afraid of the liability issues if*

### • Teachers' misperceptions about brain injury:

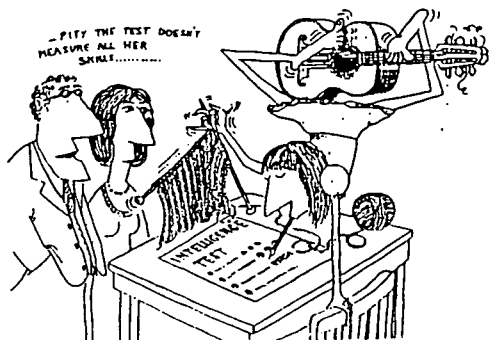
*His teachers tended to only focus on the fact he had previous behavior problems and didn't recognize the contribution of the head injury*

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

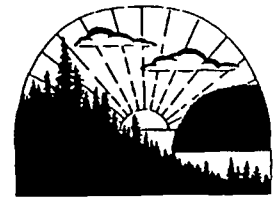
### • Schools' inability to adjust their regimen to the needs of the TBI student:

*They couldn't give my son the breaks he needed because they felt it was disruptive to the other students*

These results as well as the results from a survey of educators (see the last issue of TBI Update, 2/94) point to the many challenges faced by students with TBI, their parents, and the educators who serve them. To ensure that educational experiences for students with TBI are successful, intervention efforts need to address issues such as those that have been identified as most critical by potential "consumers".



## Getting the Insider's Perspective: Longitudinal Qualitative Study



TBI Inservice Project

One of the objectives of our work in pediatric brain injury is to clarify what the issues are for students, parents and teachers as students with TBI progress through school. In order to get a view of the issues from the perspectives of these "insiders," the project is conducting an intensive three-year study with five Oregon students with TBI.

The students range in age from preschool to high school; they vary in terms of how old they were when they experienced their injuries, the extent of their injury, and how long ago the injury occurred, giving us the ability to study a range of educational and developmental issues. All receive special education services but are integrated into regular classrooms.

Last year, the first year of the project, a field researcher was assigned to each of the five students. The field researcher observed in the student's school for about 3 hours each week, and then wrote detailed accounts of what was observed. In these "participant observations" we tried to get a sense of what school was like for the student, what it was like to be the teacher or assistant working with the student, and what it was like to be a classmate of the student with TBI. Field researchers also interviewed parents, teachers, and support staff who worked with each student. From the interviews we learned what challenges families and educators face when a student with TBI returns to school, what they find helpful and what other supports they would like to have. A detailed report of our qualitative study will appear in the next volume of "TBI Update".

This year we are continuing to observe regularly, with a special emphasis on studying students' transitions to new grade levels and, in one case, to a new school. We are pleased this year to be able to offer assistance to families and teachers of the five students, based on what we learned last year about the needs they identified. For example, we have attended IEP meetings and conducted an inservice on TBI for the teachers of a middle school student and we are meeting with teachers of two other students to talk about academic accommodations and behavior management techniques. Teachers of two students are planning to attend the Building Friendships training to help facilitate students' social integration. Through the continuing observations and interviews we will learn whether these interventions are helpful to students and staff, or whether more intensive support is needed.

One of the students in the longitudinal study is in a region where a TBI Inservice Team is being trained. (See "What's Happening with TBI Inservice Teams" on p. 1). We will encourage his teachers to contact the team for assistance, and thus will have a front row seat to observe how team intervention impacts students, educators, and parents. This will help us modify team training to make it as beneficial as possible to trainees, educators with whom they are consulting, and ultimately to students with TBI.

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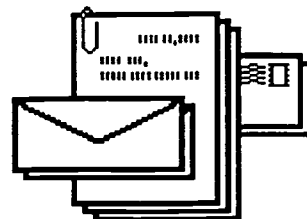
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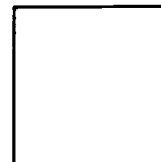
OHIF  
1118 Lancaster Drive NE  
Suite 345  
Salem, OR 97301  
(800) 544-5243 (out of state)



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Building Friendships/TBI InserviceProjects  
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99 W. 10th Ave., Suite 337C  
Eugene, OR. 97401  
Phone: (503) 346-0597  
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