

EDITORS' NOTE: *The Forum section of the Journal of Positive Behavior Interventions provides for an exchange of opinions, perspectives, ideas, and informative personal accounts. We welcome brief articles from family members, professionals, friends, advocates, administrators, researchers, and other individuals who are concerned with behavioral support issues. The purpose of the Forum is to facilitate a constructive dialog among our many stakeholders regarding important issues in practice, research, training, program development, and policy.*

In this issue, we present an article that describes the strategies a behavior support team used to help a family in a time of crisis.

The crisis involved the scheduling of invasive surgery for the mother (and principal caregiver) of a child with autism. The team developed a number of procedures for effectively preventing the occurrence of problem behaviors that had appeared during previous stressful situations. The outcomes of the approach were quite favorable for family functioning in many interesting ways. Readers may find the article to be thought provoking and encouraging regarding future efforts in developing the preventive aspects of positive behavior support.

A Family-Centered Prevention Approach to PBS in a Time of Crisis



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Abstract: This article describes a family-wide prevention approach to positive behavior support (PBS) interventions during a period of potential crisis for a family with a child with autism. Specifically, the mother in this family was to have major invasive surgery that would require extensive time for recovery. Past functional assessment data and anecdotal evidence indicated that lack of predictability, structure, supervision, and systematic behavior supports all contributed to problem behaviors in this family. As a result, a multicomponent intervention plan was implemented to prevent such problems. The procedures included the following elements: (a) priming intervention, (b) stakeholder meeting, (c) coordination of services and schedules, (d) family-wide PBS plan, and (e) ongoing support. The outcome of this intervention was that the child with autism and her siblings showed decreases in their disruptive behaviors (as opposed to the expected increases), and the family experienced other family-wide collateral positive effects from this proactive intervention approach.

This article describes a proactive intervention plan developed with a family-wide perspective. The plan's emphasis was on prevention, and it also focused on other important themes of positive behavior support (PBS; Carr et al., 2002; Horner, 2000; Horner & Carr, 1997; Horner et al., 1990; Koegel, Koegel, & Dunlap, 1996). The family that participated in this particular intervention is involved in a larger study through our center that is evaluating the effects of comprehensive, long-term PBS intervention for individuals with severe behavior problems and their families. The child participating in our study, Kelly Smith

(pseudonym), was a 7-year-old girl with autism who displayed a variety of behavior problems such as tantrums, aggression toward siblings, noncompliance, and running away. Of the other four children in the family, two showed evidence of disabilities. Mr. Smith, Kelly's father, had a particularly demanding and stressful work schedule, and Mrs. Smith, Kelly's mother, had been diagnosed with a long-term chronic illness with physically debilitating symptoms. Overall, the Smith family presented many complex issues that were important to consider in developing PBS interventions.

The Need for a Proactive Approach

The particular intervention described in this article arose out of the family's need for intensified services when we learned that Mrs. Smith was going to require major invasive surgery due to her chronic illness. She would be incapacitated for approximately 20 weeks. She was in the hospital for slightly more than 1 week, followed by 6 weeks of incapacitation during recovery and several more months of less intensive recovery.

The Smith family had been clients at our center for several years, and our previous experiences with the family members indicated that this situation had the potential to be very difficult for them because it presented possible challenges similar to those with which they had struggled in the past. Specifically we had observed that when unstructured or unpredictable situations arose, the potential for problem behaviors increased and the stress level of the family intensified. For example, this pattern had occurred over the summer when the family attempted to go on a vacation. They had never tried to take a family vacation before because of Kelly's severe disruptive behaviors, so this was a significant step for them. They came home early, however, due to severe behavior problems exhibited by Kelly that caused too much stress for the parents to handle. Kelly was aggressive toward her siblings, had several extended tantrums in public places, and repeatedly ran away (which was a definite safety hazard, as they were vacationing in a national park in the mountains). The Smith family had experienced similar difficulties during other breaks from school, during new activities or at new places in the community, and in other similarly unpredictable and unstructured settings. Functional assessment data and anecdotal evidence indicated that lack of predictability, structure, adequate supervision, and systematic behavior supports all contributed to increases in behavior problems during certain times (such as the family vacation and school breaks). We therefore believed that it would be very important to take a more proactive and preventative approach in providing support during Mrs. Smith's surgery and recovery process. In contrast to their many negative experiences, such as the family vacation, our goal was for the Smith family members to experience a positive outcome.

The Proactive PBS Intervention

In keeping with a comprehensive PBS model, we implemented a multicomponent, family-wide intervention prior to Mrs. Smith's surgery. The first goal of this intervention was to prevent behavior problems from arising due to the unpredictable nature of having Mrs. Smith in the hospital for a week, followed by months of recuperation and limited mobility. To address this goal, a priming intervention was implemented. The second goal was to implement

a temporary system of support to avoid the lack of predictability, structure, and supervision that would occur as a result of Mrs. Smith's incapacitation. In addition, because of Mr. Smith's work schedule, the five children required some way to handle supervision, transportation, and coordination of their schedules, which was usually done by their mother. To address these concerns, a stakeholder meeting was held to coordinate all necessary services and schedules, including the newly required respite care. Finally, it was our goal to further prevent disruptive behavior and motivate appropriate behavior; therefore, a systematic behavior support system was implemented in the form of a family-wide PBS plan.

It is important to note that although the family required intensive support during this time, coordination of these services was not any more labor intensive or costly than the regular ongoing intervention. As clinicians, we were not required to exert additional effort; rather, we focused our efforts specifically on coordination of this intervention instead of other ongoing areas of need.

The PBS intervention developed by the clinicians at our center was based on key features of model PBS programs that have been described in recent literature (Dunlap, Hieneman, Kincaid, & Duchnowski, 2001; Lucyshyn, Dunlap, & Albin, 2002). Several features identified by Dunlap et al., which have also been suggested elsewhere in the literature (Koegel et al., 1996; Lucyshyn et al., 2002), were important in our intervention planning. These were prevention, collaboration, effective instruction, a functional perspective on problem behaviors, and a focus on inclusion.

PRIMING

First, a priming intervention (Wilde, Koegel, & Koegel, 1992) was implemented by the center clinicians to prepare the three younger children for what to expect during this time when the structure of their lives would be quite different from the usual. The purpose was to expose them to what was going to happen in a concrete and systematic manner such that they would be better able to predict how different life at home would be for this extended time period. The intervention was important in terms of the features of model programs in two ways. First, the purpose of priming relates to *prevention*, in that the goal is to prepare the child in advance concerning what to expect and the purpose is preventing disruptive behaviors. Second, priming is a systematic method of instruction with a literature base that has demonstrated its efficacy. These are two important criteria of *effective instruction*, another feature of model programs (Dunlap et al., 2001).

Specifically, our priming intervention involved making a calendar with the children and writing on each day of the calendar where their mother would be, how she would be feeling, and how they needed to behave around her. For

example, on her first day home from the hospital the calendar said, "Mom comes home today. Her legs have 'owies' that hurt. We shouldn't touch her." This structured calendar gave the children a concrete way to understand what was happening and allowed them to predict how things would change from day to day during their mother's recovery time. Because it was presented to the children as an art project, the intervention also became a fun and motivating family activity.

STAKEHOLDER MEETING

Another feature of model programs is *collaboration* (Dunlap et al., 2001; Koegel et al., 1996; Lucyshyn et al., 2002). Dunlap et al. stated that "it provides a forum for open communication, sharing of resources, and coordinated effort" (p. 44). The second part of the intervention therefore consisted of a family-wide PBS plan and coordination of services. To coordinate these plans, the clinicians from our center organized a collaborative meeting involving all of the family members, the clinicians, the respite providers, and other relevant stakeholders. Arranging this type of meeting required that we plan in advance with all relevant participants so that everyone was aware of the purpose and importance of the meeting and could attend on the same date. This team consisted of approximately 20 people: 7 immediate family members, grandparents, respite providers, the housekeeper/nanny, a Spanish translator for the housekeeper, and two clinicians from our program who were responsible for coordination and intervention planning during the meeting and throughout the duration of Mrs. Smith's incapacitation. The purposes were to (a) coordinate coverage of respite hours for all times that the children were not in school, (b) coordinate driving schedules such that the children could maintain their individual schedules of activities and therapies (speech, occupational therapy, counseling) outside of school, and (c) develop a family-wide PBS plan. This collaborative plan is described next.

COORDINATION OF SERVICES AND SCHEDULES

Coordination of respite coverage for all hours that the five children were home from school was particularly important because we knew that lack of supervision was a potential setting event for problem behavior. During the stakeholder meeting, we arranged a daily schedule to determine who would provide services on which days (weekdays and weekends) to cover the 2 months following Mrs. Smith's surgery. In addition, the clinicians helped the family recruit respite providers and trained them in methods of PBS to ensure that they would have the tools to handle any possible behavior challenges. Because finding and training competent respite providers is often difficult, it was an important part of services coordination. Respite

providers were selected from a pool of interested undergraduates at the university where the center is located. This process was easier than might be expected because many undergraduates were eager to participate in this human service-related experience. Furthermore, these respite providers required surprisingly little training to perform successfully in the restricted aspects for which they were responsible. The family received temporary funding (for several months) from the state center for children with developmental disabilities to pay for these services as well, as this intensive level of respite coverage might otherwise have been a drain on their finances.

Each of the five children also had a variety of different activities to attend on a weekly basis; therefore, it was important that we coordinate transportation schedules for each day. Respite providers were responsible for making sure that all five children were transported to and from school, to extracurricular activities such as soccer and football, and to therapeutic appointments such as counseling and occupational therapy. Because an *emphasis on inclusion* (Dunlap et al., 2001) was very important for Kelly, her extracurricular activities with typically developing children remained a priority, even during this very stressful time. We also felt that Kelly's regular schedule and routine provided structure that would be important in preventing problem behaviors. At the stakeholder meeting, we recorded all of these schedules and commitments on an additional daily calendar to alleviate confusion and breakdowns in communication. The two calendars (the priming calendar for Mrs. Smith's surgery and the calendar for daily activities, respite coverage, and driving schedules) were placed on the living room wall so they could be referred to regularly.

FAMILY-WIDE PBS PLAN

In addition to coordination of services, we developed a family-wide PBS plan with input from all of the relevant care providers (e.g., respite, grandparents), because we knew that systematic behavior plans had important positive effects on behavior for this family. Once developed, this plan was implemented by the care providers on a daily basis. The PBS plan was developed in keeping with a *functional perspective on behavior* (Dunlap et al., 2001; Horner, 2000; Horner & Carr, 1997); that is, we were aware from previous functional assessment information that unstructured and unpredictable times were important factors in the maintenance of problem behaviors for Kelly and her siblings. As an addition to the other interventions designed to prevent such behavior, we felt it was important to provide "positive consequences to encourage appropriate behavior and deter problem behavior" (Dunlap et al., 2001, p. 45). This plan consisted of a chart where each child could earn points for engaging in appropriate behavior. Specifically, each child chose a chore for which he or

she would be responsible, such as taking out the trash, getting the mail, and helping with laundry. The children also generated with our assistance a list of expectations for good behavior, such as cleaning up their toys, not fighting with one another, and making sure not to accidentally hurt their mother's legs (e.g., by jumping into her lap). We then devised a system such that all relevant care providers would provide points for doing chores on a daily basis and following the behavioral expectations. Reinforcers that the children already received periodically in a noncontingent manner were then incorporated into the system such that they became contingent on good behavior and taking responsibility. For example, instead of simply giving the older boys spending money, a system was devised such that they earned the money contingent upon completion of their assigned chores and their appropriate behavior.

ONGOING SUPPORT

Because the clinicians were responsible for coordination of services and intervention during this time, it was important for them to continue twice-weekly visits to the house to troubleshoot problems, provide further coordination, and modify the behavior plan as necessary. We were pleasantly surprised during this time because no problems arose, and everyone involved successfully handled their responsibilities independently. Respite providers were prepared in advance, reducing difficulties in handling problem behaviors. In addition, because all of the scheduling and driving had been coordinated in advance, problems regarding communication and coordination of schedules were prevented.

Outcome

CHILD WITH AUTISM

Based on our regular, twice-weekly observations and anecdotal reports from the family and treatment providers, we found the following:

1. Systematic observations showed no evidence of major behavior problems.
2. During interviews with family members and respite providers, no one reported any behavior problems, thus providing social validation for our more systematic observations.
3. Interviews with Kelly's teacher and aide indicated there were no behavior problems, thus providing social validation that no behavior problems were occurring in the school setting.

Our observations indicated improvement in behaviors for all five children, which was also supported by our interviews with family members, respite providers, and school personnel. It appeared that the outcome during this un-

structured, unpredictable time was in marked contrast to previous situations with similar characteristics (e.g., the family vacation). Kelly did not engage in any significant problem behaviors or "meltdowns," as the family called them. She enjoyed having respite providers at the house and was very cooperative. In fact, her mother described her as being "a little angel during all of this." Mr. Smith noted that "things are going swimmingly well." As Mr. and Mrs. Smith had been very comfortable communicating their concerns and opinions to us in the past, we believed their comments to be accurate indicators of their experience during that time. If behavior problems had been occurring or other difficulties had arisen, they would have readily communicated these concerns to us. The situation remained positive and stable for the duration of Mrs. Smith's recovery and continued afterward as well.

COLLATERAL EFFECTS ON OTHER FAMILY MEMBERS

Of particular interest are some of the outcomes that we observed among the other children in the family. Specifically, the oldest son, who often engaged in many problem behaviors himself (some developmentally appropriate to adolescence and some as a result of social difficulties related to his disability), seemed to take on a sense of responsibility for his family that he never had before. We observed him engaging in a variety of new tasks, such as serving dinner to his younger siblings, unloading the dishwasher, and taking increased responsibility for caring for the family dog. His behavior problems seemed to decrease, possibly as a result of the feeling of responsibility that he was experiencing. He seemed to feel that he was a valued member of the family who had an important role that others could not fulfill because he was the oldest child.

We also noticed that the other three children seemed to rise to the occasion. The two preschool-age children played nicely together and with their sibling with autism, and all three young children followed directions and minded the rules. We were impressed by the fact that the rate of problem behaviors among all five children seemed to decrease during this stressful family situation rather than increase, as might have been expected without a proactive PBS plan in place. Finally, as a result of these positive outcomes we did not observe any major increases in parental stress (any more than would be expected under these circumstances). In contrast to the problems that occurred during their family vacation, Mr. and Mrs. Smith were very positive about this process and outcome.

Emerging Themes

Several important themes emerged from this process. First, it appeared that intervention from a family-wide perspective had pervasive effects on the family system, which might not have occurred if only one child had been the

focus of intervention. It appeared that through this approach, not only Kelly, but also her siblings, her parents, and all other involved stakeholders benefited. Second, in keeping with the hypothesis that was the basis for our intervention (taking a proactive approach during unstructured and unpredictable times), we successfully avoided a potentially problematic situation and promoted appropriate behavior. As a result, a potentially very challenging obstacle actually resulted in *improvements in behavior* the entire time that Mrs. Smith was in recovery. In contrast to similar situations in which the family experienced crises (e.g., the family vacation) this time period represented a positive outcome to a potentially difficult situation for this family. Emerging themes also raise additional questions:

1. What kinds of additional strategies and supports might we as a field need to consider in order to make family support more likely and feasible?
2. Do we need better tools for assessment that focus on the family as the unit of analysis?

These and other similar questions may be important areas for future research.

Based on our observations and anecdotal reports from the family, respite providers, school staff members, and others, further research in this area may be very important. Empirical support for preventative and collaborative approaches to behavior problems is just beginning to emerge in the literature, and these and other features are cited as important in developing exemplary programs (Dunlap et al., 2001; Koegel et al., 1996; Lucyshyn et al., 2002). Based on experiences like the one described here, as well as the recent literature in this area, we believe that this may be a very important avenue to pursue in the development of the field of positive behavior support.

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