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CHAPTER 12

Extending Behavior Support in Home and Community Settings

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CASE HISTORIES

We begin this chapter by introducing two new case examples.

Juanita

Juanita was a 5-year-old Hispanic girl diagnosed with autism. Her symptoms were archetypal—delayed communication, social isolation, and repetitive play with a limited number of toys. Juanita's mother attended parent education classes, where she learned procedures to encourage Juanita to communicate her needs. As a result of her mother's diligence in prompting expressive words, Juanita's disruptive behaviors greatly decreased, and she was able to use short phrases to express her needs and desires. Juanita demonstrated steady and consistent progress, but all of that changed when her little sister was born. Juanita took little interest in her sister throughout the

day, but her mother reported that every meal was interrupted by disruptive and aggressive behavior. She said that family meals were miserable and they had not been able to enjoy a meal for months.

Jimmy

Jimmy, a 4-year-old European American boy, was also diagnosed with autism. Jimmy's father worked outside of the home, and his mother stayed at home with him. Like Juanita's mother, Jimmy's mother participated in a parent education program and learned how to prompt communication throughout the day. As a result, Jimmy's behavior problems decreased, and he regularly used short phrases to communicate his needs and wants. However, when Jimmy's brother was born, there was a significant increase in his problem behavior. Although he had had tantrums in the past, he had never been aggressive until the baby was born. At first, Jimmy appeared to be bothered by the infant's crying—a sound that many people find annoying. He covered his ears and left the room. This adaptive response seemed to work fine in most situations.

As the baby grew, Jimmy continued to use his adaptive strategies, but not all of them worked in every situation. For example, car rides with both children were a problem. Jimmy found the crying unbearable, and since he was unable to leave the car, he began lashing out at the infant. He pinched and hit his brother. Of course, that did not stop the crying; it only made it worse. Jimmy's mother threatened him, yelled at him, and reprimanded him, but nothing worked. At times she reported that she even had to pull the car over to calm the baby down after Jimmy hit him. Further and more intense aggression was observed when the baby brother began to crawl. Fascinated with toys, on occasion he took one of Jimmy's. Jimmy pushed his brother to keep him away from the toys, and shortly afterward he began pushing the baby every time he got near the toy area.

These examples illustrate the diverse challenges experienced by families of children with disabilities. Working with such families in home and community settings necessitates considering a number of variables in order to assure that supports are acceptable, they can be implemented easily, and that they are effective in both the short and long terms. This chapter discusses a number of important variables that improve the likelihood of "goodness of fit" when teams are providing comprehensive support to families of children with disabilities in home and community settings. Home–school coordination is desirable and beneficial for all children, with and without disabilities. However, the need for a behavior support plan in the home depends on many variables, such as the settings where problem behaviors occur, the intensity of the problem behavior, the skill and consis-

tency of parents in delivering interventions, and so forth. Following a discussion of family support and general areas to consider in working with families, specific steps for developing a plan for home and community settings are discussed. Finally, the cases of Juanita and Jimmy—two young children for whom we developed home-based support plans—are described further.

UNDERSTANDING THE CONTEXT OF FAMILY SUPPORT

Overview of Family Support Issues

Over the years, the literature in the areas of disabilities and positive behavior support (PBS) suggests that family members are crucial components who must be considered in the development and implementation of support programs for children with disabilities (Dunlap & Robbins, 1991; Dunst & Trivette, 1994; Dunst, Trivette, & Deal, 1994; Lucyshyn, Albin, & Nixon, 1997; Prizant & Wetherby, 1989; Singer & Irvin, 1991; Turnbull, Blue-Banning, Turbiville, & Park, 1999; Vaughn, Clarke, & Dunlap, 1997). Recommendations for family support have been made by many family support movements, such as the Family Resource Coalition; by the U.S. Department of Health and Human Services; and in laws dating back to the Education of the Handicapped Act Amendments of 1986 (P.L. 99-457; Dunst & Trivette, 1994). In addition, most well-established intervention programs, such as those for children with autism, have a family component, which usually involves some form of parent education and other types of family support. Some examples of programs and models with this component include the Treatment and Education of Autistic and related Communication handicapped CHildren (TEACCH) program (Schopler, 1989), the early intervention model used by Prizant and Wetherby (1989), the May Center's model (Campbell et al., 1998), Pivotal Response Intervention (Koegel, Koegel, Harrower, & Carter, 1999), and Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP; Strain & Hoyson, 2000). Furthermore, a survey of "experts" in the field of autism found that family support and family and child involvement in community programs emerged as areas that are important to address in intervention and research (Pfeiffer & Nelson, 1992). Clearly, comprehensive programming across settings is needed.

Lucyshyn and Albin (1993) have proposed several family support best-practice themes, which are also endorsed elsewhere in the literature. These include (1) the importance of understanding the ecology of the family; (2) the development of collaborative partnerships between parents and professionals (Dunlap & Robbins, 1991; Turnbull et al., 1999); (3) the identification of family strengths and the child's positive contributions; (4) the devel-

opment of standards and practices that strengthen family members and build on their existing skills and resources (Dunst, Trivette, & Deal, 1994; Lucyshyn et al., 1997); and (5) the identification of sources of stress for the family (Singer & Irvin, 1991). Many researchers have noted the importance of such practices in enabling and empowering families (Dunst & Trivette, 1994; Dunst et al., 1994; Robbins, Dunlap, & Plienis, 1991; Ruef, Turnbull, Turnbull, & Poston, 1999; Singer & Irvin, 1991; Turnbull et al., 1999). Specifically, family empowerment is an important area of focus in this literature (Dunst et al., 1994). Enabling the family in this manner emphasizes the importance of viewing the family members as members of the support team and as "experts" in their own right. In short, PBS also focuses on support for the family, not just the child. This in turn helps family members support their child in meaningful and productive ways.

Variables Affecting Family Members' Response and Adjustment to Disability

The literature on family support interventions posits that a family's overall response to the circumstances presented by having a child with a disability will result from the interaction of many variables (Robbins et al., 1991; Turnbull & Ruef, 1997). These variables may include "social dynamics with the family unit, cognitive appraisal and coping strategies, practical resources, and social support from outside the family" (Singer & Irvin, 1991, p. 291). Therefore, intervention must take all these variables into account, and must have a family-oriented focus (as opposed to an individual-child-oriented focus), if it is to be successful in reducing family stress, enhancing coping, promoting skill development, and empowering families in general. Incorporation of ecocultural theory (Gallimore, Weisner, Kaufman, & Bernheimer, 1989) is important as well, since consideration of variables related to culture, values, and family priorities is crucial in developing support plans that exemplify "goodness of fit." That is, effective family support considers the particular family's unique environment, as well as its cultural values. This will enhance the success of child interventions.

A particularly critical area that warrants consideration is the family members' emotional reaction to having a child with a disability. Family members, by necessity, make adjustments in their daily routines to accommodate the special needs of a child with a disability. Regardless of how they may negotiate the logistics of their daily routines, however, they often experience a number of negative emotional responses to caring for such a child. Family members (including siblings) of persons with a variety of disabilities may experience higher than average incidences of family stress and depression (Bristol, Gallagher, & Holt, 1993; Singer & Irvin, 1991). Many

sources of stress are associated with raising a child with special needs, all of which may influence family members' adjustment to the disability. Receiving the initial diagnosis of a disability can be both surprising and stressful for parents. An added source of stress may be uncertainty about the cause of the disability. Furthermore, child characteristics may affect stress levels in parents. For example, more severe disabilities require a greater amount of effort on the part of care providers, thereby influencing stress. Many parents also report a critical lack of trained personnel with whom they feel comfortable leaving their children, which in itself often causes clinical levels of stress among parents (Koegel et al., 2002; Moes, 1995; Moes, Koegel, Schreibman, & Loos, 1992). When one considers the increased responsibilities involved in caring for a child with disabilities, coupled with the lack of acceptance that still persists in mainstream American society, it is no wonder that many primary caregivers in particular report higher levels of stress related to their children's symptoms, increased levels of isolation, greater health issues such as fatigue and illness, and more depression than parents of typically developing children do.

Community reactions to persons with disabilities also influence the context in which the family lives. Generally, the more severe a child's symptoms, the more isolated parents are likely to be from the community, because people do not typically know how to react to an individual with a severe disability. Turnbull and Ruef (1997) examined parents' perspectives on lifestyle issues and support for children with problem behavior, in relation to inclusion issues. The parent interviews revealed several themes regarding inclusion of their child across environments. For instance, parents reported that it was nearly impossible for them to participate in preferred religious activities, for reasons including attitudes and competencies of religious staff, the formal and structured nature of the services, and difficulty in obtaining age-appropriate groupings. Religious involvement can be a source of community support; however, when participation is difficult, it may lead to more social isolation.

In addition, when looking specifically at family members' relationships with the child, parents consistently commented on sibling relationships. Parents reported that specific challenges included lack of a close bond between the child with problem behavior and his or her siblings, frustration or embarrassment, and resentment about the amount of time and attention devoted to the sibling with problem behavior.

Still another source of stress concerns transition issues as a child moves into adulthood. Parents of a child with a disability may be concerned about their child's move out of the house, self-sufficiency, and marriage. The caregiving responsibilities of these parents are more likely to continue into adulthood. This leads to concern about what will happen to the child after the parents are unable to care for him or her.

Parent and Family Empowerment

The concept of *parent and family empowerment* is an important goal and outcome of support programs (Mahoney et al., 1999; Turnbull & Turnbull, 2000). Although *empowerment* has traditionally referred to advocacy, the term now refers to parents' and other family members' collaboratively participating in their child's behavior support. An empowered parent is one who demonstrates confidence and effectiveness in teaching his or her child, successfully manages daily routines, interacts well with school personnel and other service providers, and is able to obtain services for the child (Koren, DeChillo, & Friesen, 1992). Conversely, an unempowered parent may exhibit behaviors and attitudes that reflect frustration, stress, depression, helplessness, and overall dependence on professionals. Interventions aimed to empower parents enable them to acquire competencies to solve problems, meet their needs, and attain family goals. Some hypothesize that empowering parents will lead to greater child gains. In fact, studies have shown that interventions that utilize parent participation, wherein parents take an active role in intervention implementation, result in greater child improvement and increased generalization of treatment gains (Koegel, Koegel, & Schreibman, 1991).

Parent–Professional Partnerships

The *parent–professional partnership* model of support is an approach that aims to empower parents. Such a partnership includes jointly developing a support plan that will fit into the family's daily routines, as well as an emphasis on family choice and decision making. That is, not only are parents (or other primary caregivers) involved in developing the supports, but they are also the ultimate decision makers in goals and implementation (Allen & Petr, 1996). It is hypothesized that interventions developed in this way are more likely to be competently and consistently implemented. Dunst and Paget (1991) have defined a parent–professional partnership as a relationship between family members and professionals who work collaboratively, using agreed-upon roles and common goals. Lucyshyn, Horner, Dunlap, Albin, and Ben (2002) have provided a comprehensive definition of collaborative partnerships with families in the context of PBS interventions:

> [Such a partnership involves] the establishment of a truly respectful, trusting, caring, and reciprocal relationship in which interventionists and family members believe in each other's ability to make important contributions to the support process; share their knowledge and expertise; and mutually influence the selection of goals, and design of behavior support plans. . . . the traditional expert–client dichotomy is transferred into an equal partnership in which fam-

ily members and practitioners offer complementary expertise, solve problems together. . . . (p. 12)

Overall, this type of partnership involves professionals supporting parents in problem solving related to the child, rather than directly solving problems for the parents. Whereas parent educators should be responsible for assuring that parents have specific skills and techniques designated to help their child, the parents are responsible for choosing how the techniques are applied in their particular family (Turnbull et al., 1999; Turnbull & Turnbull, 2000). In a partnership between parents and professionals, the professionals may be the "experts" in particular procedures, while the parents are the "experts" on their own child and should be responsible in deciding how the procedures are incorporated into the family's daily routines. Table 12.1 provides examples of ways that professionals can structure their interactions with parents so that they reflect a true partnership, rather than being directed by the professionals.

Now that we have discussed general issues regarding parenting of a child with disabilities, there are a number of considerations that will enhance the PBS process and the effectiveness of a support plan. These are presented below, followed by specific suggestions for developing home-based support programs.

CONSIDERATIONS FOR FACILITATING COLLABORATION WITH FAMILIES IN PBS PROGRAMS

Consideration 1: Has an Alliance with the Family Been Established?

Establishing an alliance with the family is critical before a behavior support plan can be implemented (Dunlap & Robbins, 1991; Dunst & Trivette, 1994; Lucyshyn & Albin, 1993). This process necessitates ongoing and open communication with and feedback from the family. Finding a good match between professionals and family members is also an important consideration. Specifically, cultural and linguistic issues should be considered; matching people who are of similar cultural and linguistic backgrounds is likely to result in a more appropriate support plan. When this is not possible, the professionals should educate themselves regarding the culture of the family (see Consideration 4, below). Similarly, some families have a preference for male or female professionals. Finally, personality matches have been reported to be important to families. Some family members report that their child responds better to very animated, outgoing persons

TABLE 12.1. Examples of Professional Directed Interaction versus Parent–Professional Partnership in Parent Education

Goal	Professional directed interaction	Parent–professional partnership
Identification of naturally occurring opportunities for language during parent education session	Professional: "It looks like John is interested in playing with the ball. Let's try having him say 'ball' for you to throw it to him."	Professional: "It looks like John is interested in playing with the ball. What opportunity for language would you like to target in this activity?" If the parent needs more specific suggestions, the clinician may add: "There are a number of choices, such as . . . what would you like to try?"
Identification of naturally occurring opportunities in the family's daily routines	Professional: "You can use the same techniques at home by having Katie make a verbal attempt for 'juice' before giving her juice when she expresses interest."	Professional: "It is useful for you to identify opportunities for Katie to make verbal attempts throughout the day. Can you identify any opportunities that would fit in your daily routines?"
Setting of parent education session	Professional: "I think that it will be helpful for us to have a few sessions at home, since that is where you spend most of the time with your child."	Professional: " Where do you think it would be most helpful for the sessions to occur?" Or "We have a couple of options for the setting of our sessions . . . which of these would be most useful to you?"
Identification of target behaviors	Professional: "I think that we should first work on labels of your child's most highly desired activities, such as . . . "	Professional: "Do you have any words that your family finds particularly important for your child to learn?" Or "We often start by targeting . . . which of these would be the most appropriate and useful for your family and your routines?"
Points targeted for feedback	Professional: "Let's focus on maintenance tasks today."	Professional: "Which of the points in the manual that we have covered would you like to focus on today?"

who enjoy gross motor activities, while others report that they prefer calmer and quieter individuals. In short, establishing an alliance with the family so that a program provides a good "match" for a family is likely to enhance the overall effectiveness of the program (Koegel et al., 2002).

Consideration 2: Does the Team Understand the Family's Priorities?

Goals for intervention should be based on the family's priorities combined with the assessment information, and should be mutually agreed upon by professionals and family members. Mutual goals are most likely to be pursued by the family members, since they will be motivated to attain these goals. Likewise, professionals are most likely to be invested in certain goals if they see them as important for the child or individual with a disability.

Research has repeatedly shown that supports addressing goals that are not coordinated with the family members, or that the family members do not consider to be of value, will not be implemented or maintained over time (Steibel, 1999). Support plans that are not coordinated across environments can be ineffective. For example, Dunlap, Koegel, and Koegel (1984) demonstrated that toilet training pursued in individual settings (e.g., school or home) without systematic efforts to coordinate training across environments were minimally effective. In contrast, programs that offer a continuity of intervention across environments may enjoy rapid and durable success. Again, this points to the importance of developing goals as a team, so that there is "buy-in" from all participants.

Consideration 3: Can Supports Be Incorporated into Family Routines?

It is critical that the support strategies to be carried out by family members can be incorporated into existing family routines. Parents of children with disabilities report increased stress and difficulty implementing support strategies that require them to set aside time to work with their children in a one-on-one format. In contrast, when interventions can be incorporated into daily routines, families report a reduction in their stress levels and increases in teaching episodes (Koegel & Koegel, 1995; Moes & Frea, 2000; Steibel, 1999). However, this process necessitates extensive and ongoing collaboration and alliance with a family. An alliance must be established wherein the professionals and the family members are able to determine the family's values and priorities, have a good feel for the family's daily activities, and develop a plan that does not result in added stress and is coordinated across all care providers.

Consideration 4: Does the Team Understand the Family's Culture?

An important aspect of PBS is to consider the child in the context of his or her family, community, and culture (Koegel, Koegel, & Smith, 1997). In order to conduct a culturally appropriate assessment, it may be important to include (in addition to the immediate family) the extended family, as well as any others (godparents, etc.) who play an important role in the child's life. It is essential to determine the presenting problem *in the eyes of the family*. What are the family's expectations for the child? In addition, when a team is designing support plans, it is critical to assess individual needs of the family related to resources and constraints. For example, does the family have special language needs? Is a translator needed so that all identified participants can be included in the intervention planning? Is transportation needed? Families' cultural values have largely been ignored in behavior intervention programs, and most parent education programs have been developed and evaluated primarily with families of European American backgrounds (Forehand & Kotchick, 1996). Again, goals will be more likely to be implemented and maintained over time if each family's unique cultural needs are considered.

Another important area relating to cultural values is the perception of the presence of a "disability." In other words, many cultures do not perceive a "disability" in an extremely negative light, and therefore may not experience the sense of need or urgency for intervention services (Santarelli, Koegel, Casas, & Koegel, 2001). This is in contrast to the issues of stress described above (it should be noted that the research cited in the earlier description was again conducted primarily with European American families). Although early intervention is recommended, the degree of the problem and parental motivation for intervention may vary with the stress level of a family, and culture may play a large role in a family's stress level.

Consideration 5: Have the Family's Strengths Been Assessed?

In addition to assessing the specific goals for the family and possible constraints on implementing the support plan, it is useful to identify strengths that can be used as a foundation for the support plan. For example, does the family have a strong social support network? Does the family participate in community activities? Does the family have strong collaborative relationships with other treatment providers? What are strengths that individual family members can contribute? For instance, one child we worked with had great needs in social areas. We developed an intervention program that focused on developing relationships outside the school setting.

The family invited children over for regular play dates. However, within a short period of time, the father (who was the primary after-school care provider) began canceling the play dates. Upon closer inspection, we learned that he did not enjoy the activities in which the children engaged after school. Once we collaboratively developed a list of activities with him—which included outdoor activities he preferred and was good at, such as rock climbing at a local gym, hiking, going to the park, and bike riding—he resumed the play dates.

DEVELOPING AND IMPLEMENTING A SUPPORT PLAN

Intervention within a PBS framework is comprehensive and long-term (see Chapter 1; see also Horner & Carr, 1997). Risley (1996) has noted that behavior change that leaves a child in an isolated or restricted life is a hollow accomplishment. Thus the need for comprehensive, family-centered support is clear. A support plan must facilitate the individual's participation in a variety of family and community settings. Because community inclusion, contextual fit for families, family empowerment, and improvement in quality of life are key features of PBS, a comprehensive approach with these goals is necessary to fulfill the mission of this model.

Within the five broad steps of the PBS process as described in this book, there are several smaller strategies with particular emphasis on family contexts, which we have outlined in the sections to follow. These substeps include (1) assessment of behavior and context; (2) collaboratively developing and evaluating the interventions and goals; (3) assessment of the parent–professional partnership; (4) evaluating the goodness of fit of interventions; (5) considering the social validity and long-term importance of the goals; (6) follow-up and ongoing program assessment/monitoring; and (7) assessment of the fit of interventions within the family's daily life.

Step 1: Assessment of Behavior and Context

Importance of Assessment

Assessment in the context of family and community takes on a larger unit of analysis and a greater number of settings (Carr et al., 1999, 2002; Lucyshyn, Olson, & Horner, 1995). This broader scope of assessment is important for understanding the complex roles of the family and community. In addition to traditional functional assessment methods, Carr et al. (2002) propose that one important tool may be focus group methodology (not just the use of experts) for assessment of key variables. That is, in car-

rying out assessment, just as with intervention, it is important to develop a partnership among all involved members of the intervention team, such that each can learn from the others. In contrast to more traditional methods of assessment (in which an "expert" gives tests or does observations and presents data to others involved), PBS emphasizes the need for assessment tools that are more user-friendly and pragmatic, so that reliance on "experts" will decrease and the use of assessments by other stakeholders will increase. Some examples of these procedures are discussed below.

Collecting Functional Assessment and Baseline Data

With any behavior support plan, it is important first to collect data on the behavior for the purpose of establishing how often the behavior occurs, where it occurs, under what circumstances, and for what purpose (as described in Chapters 5 and 6). These data are important for several reasons. First, the literature notes that successful intervention planning is always based on functional assessment data (Dunlap, Kern-Dunlap, Clarke, & Robbins, 1991; Groden, Groden, & Stevenson, 1997; Horner, 2000; Horner & Carr, 1997; Lucyshyn & Albin, 1993; Lucyshyn et al., 1997). Second, during the later steps of reevaluating the intervention and its progress, it is important to have baseline data to which the intervention data can be compared, so that progress can be monitored systematically rather than haphazardly.

There are many ways to collect baseline data. Frequency data (how many times the behavior occurs in a time period) and percent occurrence (of specified time intervals, how many contain the behavior) are two of the most common. Whichever method is chosen, it is worthwhile to consider how functional assessment procedures can be incorporated into the process, so that collecting baseline data and completing behavioral assessments can be done simultaneously, if possible. Maximizing efficiency in this manner is important, because data collection can be intrusive and labor-intensive for families. Checklists (e.g., Frea, Koegel, & Koegel, 1994) are an example of one way in which both frequency and functional assessment data can be collected at the same time. If behaviors recorded over a specified time period are noted on this checklist, along with the antecedents and consequences of those behaviors, these data can be used both as assessment data (to determine functions of behaviors) and as baseline data (to evaluate current rates for future comparison with intervention rates).

Functional assessment places the focus on environmental events and considers carefully the role that such events play in eliciting, reinforcing, and maintaining problem behavior (Horner & Carr, 1997). Thus, challenging behavior is not viewed as a result of something within the individual;

rather, it is seen as the "result of challenging social situations for which the problem behavior itself represents an attempted solution" (Horner & Carr, 1997, p. 85). This focus on assessment leads to the emphasis on redesigning environments and teaching skills to the individual, as opposed to controlling/managing the person and his or her behaviors. In this way, these data can be used to directly inform support planning. All members of the team or partnership can and should be involved in carrying out these and similar procedures. It is important to note that such procedures are easily learned by "nonexpert" individuals, such as family members, and should be taught when appropriate.

Ecocultural Assessment

Another important aspect of assessment when working in parent–professional partnerships is consideration of ecocultural variables occurring in the natural context in which the individual functions (Lucyshyn & Albin, 1993; Lucyshyn et al., 1995, 1997). These assessments are geared toward understanding the child from both a developmental and an ecological perspective (Fox, Dunlap, & Philbrick, 1997). Specifically, if interventions are to take ecocultural factors into account, careful assessment of such factors must be considered. Ecocultural variables that may be important to assess include socioeconomic status (SES), family values, beliefs about parenting, philosophies on education and inclusion, number of family members living in the household, constraints on the parents' time, and many more. Some formalized measures for assessment in this area, such as the Ecocultural Family Interview (EFI; Weiner, Koots, Bernheimer, & Arzubiaga, 1997), have been developed for use in this area (Albin, Lucyshyn, Horner, & Flannery, 1996). Additional measures have been developed for use in assessing "goodness of fit" once intervention plans have been formulated (Koegel, Koegel, & Dunlap, 1996). These are discussed in the section on evaluating the fit of intervention within daily routines.

Step 2: Collaboratively Developing and Evaluating the Interventions and Goals

Once the assessment has been completed, these data can be used to inform support planning. The specifics of supports are beyond the scope of this chapter and are described in detail elsewhere in this book; however, some broad categories of interventions typical for home and community settings are outlined in Table 12.2.

After the support plan is up and running, regular, planned reevaluation of specific interventions and goals is necessary to assure that they are still relevant and important to both the family and the individual with the

TABLE 12.2. Specific Types of PBS Interventions Relevant for the Home and Community

Type of supports	Examples	Citations
Antecedent modifications	• Modified routines • Scheduled activities • Self-help strategies (e.g., scheduled bedtime activities) • Strategic placement of items in environment	Dunlap et al. (1991); Horner & Carr (1997); Koegel, Steibel, & Koegel (1998); Lucyshyn et al. (1995)
Skill building or teaching alternative skills	• Functional communication training • Play skills • Social interaction skills • Self-care • Mobility • Problem solving • Regulation of personal physiology	Carr et al. (1999); Dunlap & Robbins (1991); Fox et al. (1997); Horner & Carr (1997); Lucyshyn & Albin (1993); Lucyshyn et al. (1997); Wetherby & Prizant (1992)
Response interventions	• Systematic reinforcement of appropriate behavior • Redirect to appropriate behavior	Horner & Carr (1997); Lucyshyn & Albin (1993); Lucyshyn et al. (1997)
Long-term family support	• Facilitation of social inclusion/participation in family activities • Education/information sharing • Respite care • Training in behavioral techniques • Counseling/emotional support • Advocacy • Personal futures planning	Fox et al. (1997); Lucyshyn & Albin (1993); Lucyshyn et al. (1997)

disability. Adjustments to plans may be needed to increase the feasibility of implementation. That is, the "kinks" may need to be addressed in any plan. One very helpful way to accomplish this goal is to have regularly scheduled meetings with *all* members of the child's team (see Chapters 4 and 11). These meetings should ideally be scheduled to accommodate all stakeholders, particularly the family. It is suggested that a plan be made in advance for regularly scheduled meetings, rather than the "wait and see" method that so many teams rely on. It is our experience that if the team decides to wait and see how the intervention goes before calling a meeting, the meeting only gets called once a behavioral crisis has occurred. At this point the focus of the meeting becomes crisis intervention, rather than evaluation of many important variables (such as progress, goodness of fit,

ongoing relevance of goals, etc.). By having a meeting schedule, team members can evaluate these important variables on an ongoing basis and can deal with problem behaviors proactively (i.e., before they occur), rather than only after a crisis has occurred. The next four steps (Steps 3–6) include areas that may be helpful to address during these ongoing scheduled team meetings.

Step 3: Assessment of the Parent–Professional Partnership

Once a behavior support program is implemented, assessment of the ongoing parent–professional partnership continues to be of critical concern. Below are some questions compiled from the literature that may help in evaluating whether a partnership has been established with the parents or other primary caregivers (Dunlap & Robbins, 1991; Dunst, Trivette, & Deal, 1994; Lucyshyn & Albin, 1993; Singer & Irvin, 1991; Turnbull et al., 1999):

1. Are the parents being viewed as the "experts" regarding their child?
2. Are the family members being regarded as resources and sources of strength for the child, rather than as persons who do not contribute to or who hinder intervention?
3. Are the goals in line with what the family members have expressed is important to them over time? Does the family agree with all of the goals? Does the family have goals that are not being addressed?
4. Are the intervention settings important to the family? Are there any settings that are not being addressed?
5. Do the family members continue to view the goals as "doable" within their daily routines? Does incorporation of these goals into daily routines increase or decrease family stress?
6. Are there any areas/sources of family stress that are not being addressed (e.g., need for respite, desire for a certain type of service, parent education, etc.)?
7. Is the emphasis on "fixing" the ecology rather than the child or family, and thereby on empowering the family?
8. Are cultural and SES factors being taken into consideration (e.g., language barriers, need for transportation, location of meetings, the family's view of the disability, etc.)?

Step 4: Evaluating the "Goodness of Fit" of Interventions

As discussed elsewhere in this chapter and book, contextual fit affects the likelihood that an intervention will be implemented successfully (Horner, 2000; Lucyshyn et al., 1997). Horner (2000) has suggested that support is

less likely to be carried out if family or staff members consider it to (1) be cruel/dehumanizing, (2) be unlikely to be effective, (3) include procedures that they do not know how to perform, (4) require time and equipment that they do not have, or (5) place them at risk of reprimand or abandonment by supervisors. In addition, support must "work" for everyone involved, and the goal in support planning is to devise a plan that is technically sound and is also a good "fit" with the values, skills, and resources of people within a particular setting (Horner, 2000). When team members are evaluating the goodness of fit of interventions, it may be helpful to consider some or all of these areas.

It is also important to evaluate the extent to which supports can feasibly be incorporated into the family's daily routines. In particular, will incorporation of supports into routines constitute a burden for the family? If an intervention procedure is considered a burden, it has likely not been well incorporated into their routine. This area is discussed further in Step 7.

Step 5: Considering the Social Validity and Long-Term Importance of the Goals

PBS plans and in-home programs always need to consider the "big picture." It is often stated that quality of life as an outcome measure (rather than changes in discrete behavioral variables) is a major and important focus of PBS (see Chapter 11; see also Carr et al., 2002). Although professionals may be helping parents learn procedures of presenting clear instructions and reinforcement, they also need to think on the global level. Questions Risley (1996) has discussed as important include the following:

- How are the child and family doing overall and over time?
- Are all family members happy, satisfied, and safe?
- Does the person have a stable home? Does the person have family and friends on which to base her or his life and future, and after whom to model her or his ways?
- Is the child independent, productive, and included in family activities?
- Is the child a participating member of the family?
- Is the person continuing to develop new interests, new friends, and new skills?

Team members often focus on individual target behaviors, such as reductions in self-injury, rather than considering the relative degree of importance of what they are teaching. The importance of such thinking in the long term is critical.

Step 6: Follow-Up and Ongoing Program Assessment/Monitoring

As discussed above under Step 2, it is important to continue monitoring the program once the initial intervention has been implemented. In addition to following the guidelines for setting up regular team meetings, several other important steps may be helpful. First, continuing assessment of the areas mentioned thus far (the partnership, goodness of fit of interventions, long-term importance/social validity of goals) will be important in maintaining a viable, successful intervention program. It is also important to note that periodically the team may need to return to Step 1 (assessment). Often as individuals make progress, new behaviors emerge, skills are acquired or are no longer relevant (e.g., using picture cards once a child learns to talk), environmental changes occur (e.g., a family move or the birth of a new sibling), and many other variables change (and therefore cause changes to antecedents and consequences). All such changes necessitate ongoing assessment. At these times it may not be enough to meet and discuss progress, goals, and the like, because further systematic assessment may be required. It is important to emphasize that these steps are actually a cycle that will need to be repeated periodically with involvement from all members of the team.

Step 7: Assessment of the Fit of Interventions within the Family's Daily Life

When team members are designing intervention programs, it is important to assess the fit of interventions and supports into the family's daily lives. Are the family members likely to implement behavior plans when the professionals are not present? The perceived demands of programs will influence the family's likelihood of following through with plans. This can be evaluated behaviorally, by assessing whether the family is actually implementing the support plan, and through discussions during ongoing interactions. In addition, if goals are developed with consideration for the family members' cultural values and their priorities for their child, the likelihood of long-term maintenance is improved (Koegel, Steibel, & Koegel, 1998).

JUANITA'S IN-HOME BEHAVIOR SUPPORT PLAN

We now return to Juanita to illustrate how a support plan was developed for her home. The first step in Juanita's program was to assess the situation and to evaluate rates of the problem behavior, prior to implementing the support plan. According to Juanita's mother, dinnertime was a problem. In

addition, the family members expressed that they did not feel comfortable having someone in the home during family dinners. In respecting the family's wishes for privacy during the dinner hour, we attempted to collect data without being there in person. The family members expressed their willingness to set up a video camera and turn it on prior to each meal, so data from each videotape were analyzed the following day.

The videotape analysis indicated that Juanita's aggressive behavior had a number of antecedents or triggers. The first trigger occurred during "down time." Juanita's mother seated the two children at the table while she finished her last-minute meal preparations and placed the food on the table. During this period of time, there was a high likelihood of aggression and disruption. Second, Juanita's baby sister had a metal tray on her highchair, which she frequently banged with her spoon. This noise always caused Juanita to become aggressive toward her sister. Third, the baby had begun to make communicative noises, which regularly caused aggression also. Another thing we noted was the proximity of the two children. During meals, Juanita's mother placed her next to her baby sister's high chair.

Mealtime therefore required a multicomponent intervention. First were some antecedent interventions. During discussions in our initial meeting to develop a plan, the family members indicated that in their garage they had another highchair with a plastic tray. The family replaced the metal tray with the plastic tray, which greatly reduced the noise that irritated Juanita. Second, when Juanita's mother realized that "down time" was a problem, she felt that it would be easy to wait until dinner was served to bring the children to the table. This eliminated a period of time when aggression was frequent. Juanita's parents also moved the high chair to the other side of the table, so that it was not physically possible for Juanita to assault the baby.

Second, a teaching component was implemented. In order to deal with the baby's communicative noises, Juanita was taught to respond differently to the vocalizations. Her parents prompted her to try to figure out what the baby was saying, instead of hitting the baby when she vocalized. The parents actually came up with many humorous examples, such as "Juanita, do you think Bonita is saying, 'I don't want Barney for dinner'?" We continued to analyze the videotapes after the support plan was in place, and after a short period of time, the aggression was completely eliminated. Furthermore, the intervention seemed to result in a lifestyle change for the family: We noted that the father was not home for dinner during many of the baseline tapes, but that after the aggression was eliminated, the father was always home and eating with the family at the table. Likewise, the family showed negative and neutral affect during baseline sessions, but showed positive affect during meals after the aggression had been eliminated.

JIMMY'S IN-HOME AND COMMUNITY BEHAVIOR SUPPORT PLAN[1]

Jimmy's mother reported that his aggressive behavior occurred during playtime and in the car. During playtime, the mother felt that someone entering the home and observing, to assist with the assessment, would not be disruptive to him. During car rides, Jimmy's mother felt that she could collect data herself. These data yielded information regarding what maintained the behavior problems.

During the playtime observations, a specific and regular cycle emerged. First, Jimmy's mother set out toys on the floor for him; second, the baby brother crawled over toward the toys; third, Jimmy pushed his baby brother so hard that he fell over, almost always hitting his head on the floor. Fourth, following each incident the mother took Jimmy's crying baby brother away from the toys, reprimanded Jimmy, then left him to play with the toys alone while she comforted the baby. In short, the aggression was serving the useful and desired function for Jimmy of getting rid of his brother and having the toys all to himself.

Analysis of the data sheets that Jimmy's mother filled out after car rides indicated that the problem behavior occurred only in the afternoons, when Jimmy's mother picked him up from preschool. The baby was placed in a car seat, which was buckled in the back seat. Often the baby began to cry, at which time Jimmy would lash out and hit him repeatedly. This caused the baby to cry more; once the baby had been hit, he would continue crying until the mother stopped the car to comfort him or until they arrived at their home.

Now it was time for us to develop a program with the parents, as a team. Each setting required a different intervention, and Jimmy's mother in particular was more than willing to participate actively in a program, as she feared for the safety of the baby. We met as a team and discussed a behavior support plan.

First was the playtime. The parents' goal was to decrease Jimmy's aggression while also developing a good sibling relationship. Therefore, the program jointly created was twofold. One part of the program involved first providing Jimmy with personal space so that his toys would not be taken by the baby. This antecedent change was made by having the parents place a small table in their living room during playtime—one that was low enough for Jimmy to play on, but high enough that the baby could not reach the top. Jimmy's mother then placed the desired toys on the table. Although this greatly reduced the behavior problems, we also wanted to respect the family's desire to create a bond between the children, so the

[1]See data for playtime in Koegel et al. (1998).

family gathered a small basket of baby toys—toys in which Jimmy had no interest, but were of great interest to the baby. Whenever the baby crawled over toward Jimmy, the parents prompted him to give the baby a toy from the basket. This served the function of decreasing the baby's interest in Jimmy's toys and providing an initial way of creating positive interactions between Jimmy and his brother. Finally, because it was important for Jimmy to have a replacement behavior for the aggression, he was prompted to say, "Mom, take Noah." After the prompt, Jimmy's mother immediately picked the baby up so that he was not near the play area. Initially, his mother prompted this functionally equivalent response on a regular basis before the baby got close to the play area (i.e., during noncrisis times); she did this until Jimmy began to use the phrase spontaneously. These three intervention components resulted in rapid and steady decreases in aggression during playtime.

Intervention for the car rides was perhaps more straightforward. We approached this from two perspectives. First, logistically, the children had to ride together on a regular (daily) basis; however, we were able to make antecedent changes by placing the car seat far enough away from Jimmy to immediately increase the baby's safety. Still, the crying could not be completely eliminated, and Jimmy did continue to scream, cover his ears, kick the back seat of the car, and try to reach out to hit the baby every time he cried. From Jimmy's perspective, the crying was quite irritating, so the parents bought Jimmy a tape player with earphones and some of his favorite tapes. Then, when Jimmy began to become upset at the baby's crying, his mother prompted him to listen to a tape. Often Jimmy's mother prompted him to begin listening to a tape as soon as he got in the car, thereby avoiding disruptive behavior altogether. These antecedent interventions reduced the aggression in the car to negligible levels.

It is important to note that the programs developed in both Jimmy's and Juanita's cases were created in partnership with their families. Their opinions, values, and strengths were considered. The interventions were developed to fit into existing and ongoing routines. The families were not required to set aside additional times to implement the interventions. Data were collected, and the children's progress was assessed on a continuing basis. Throughout all phases of support planning and implementation, the parents and other team members worked in partnership.

SUMMARY

Research supports the notion that parent education and home-based support are important components of PBS, and that teaching episodes can be

incorporated into family routines and daily life. In this way, parents and other family members will not be required to rely solely on professionals for their child to receive ongoing intervention, and they will be equipped with the tools to empower them when handling problem behaviors, capitalizing on "teachable moments," and otherwise interacting with their child throughout the day. Furthermore, a lower rate of institutionalization occurs when parents participate in parent education programs (Mesibov & Schopler, 1983). In short, parents can provide effective individualized programs; however, there are a number of important considerations when team members are developing and implementing such programs. Assuring that assessment and interventions consider the ecocultural variables, and that parents and professionals develop a PBS plan as a team, will result in an increased likelihood that programs will be implemented and that gains will be maintained over time.

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