DOCUMENT RESUME

ED 416 639 EC 306 197

| | |
|---|---|
| TITLE | Positive Behavioral Support. |
| INSTITUTION | Kansas Univ., Lawrence. Beach Center on Families and Disability. |
| ISSN | ISSN-1044-8217 |
| PUB DATE | 1997-00-00 |
| NOTE | 21p. |
| AVAILABLE FROM | The Beach Center on Families and Disability, The University of Kansas, 3111 Haworth, Lawrence, KS 66045, phone: 785-864-7600 (free). |
| PUB TYPE | Collected Works - Serials (022) |
| JOURNAL CIT | Families and Disability Newsletter; v8 n3 Win 1997 |
| EDRS PRICE | MF01/PC01 Plus Postage. |
| DESCRIPTORS | *Behavior Change; *Behavior Problems; Case Studies; *Child Rearing; *Classroom Techniques; *Disabilities; Elementary Secondary Education; Focus Groups; Information Dissemination; Intervention; Legislation; Parent Attitudes; Program Development; Research and Development; Theory Practice Relationship; Training Methods |
| IDENTIFIERS | *Functional Assessment; *Positive Behavioral Support |

ABSTRACT

This theme issue presents a variety of articles and resources on the application of positive behavioral support (PBS) with children who exhibit behavior problems in home or school settings. The first article discusses the importance of understanding a challenging behavior's purpose, implementing behavior change strategies, and monitoring improvement. Research findings on PBS from 1985 through 1996 are summarized. The next article describes the Family Connection, a project that disseminates information to families on research concerning PBS through publications and a toll-free number. A listing of state training team coordinators is provided, followed by an article on stakeholder perspectives based on the input of 12 focus groups. The next article reports on a research study that examined the perspectives of 86 parents of children with disabilities and challenging behaviors. Characteristics of a model statute on positive behavioral support are then listed and explained. Three stories of individuals and families illustrate the practical application of PBS. The final two articles explain the functional assessment of behavior and list 10 ways to support a person with challenging behavior. (DB)

THE UNIVERSITY OF KANSAS
Beach Center on Families and Disability

# Families and Disability Newsletter

Volume 8, Number 3 Winter 1997

## Positive Behavioral Support

Have you ever heard the phrase, "Treat the symptom, ignore the disease"" Many people handle discipline that way. They try to eliminate disruptive or dangerous behavior without looking into why the behavior occurred.

Positive behavioral support is different—even revolutionary—because it is based on asking "Why?" Why does Pat never seem to sit in his seat at school? Why does Richard bang his head repeatedly? Why does Anastasia wander off?

Behavior usually happens for a reason. For example, an individual may use it seeking attention or self-stimulation. Behavior can be a form of communication—particularly for people with limited language capabilities—that may express frustration, anxiety, physical pain, other emotions, or needs.

When students throw objects in the classroom, they may be expressing a need for attention. Yelling may be their way to get out of an assigned task. Or they could be exhibiting challenging behavior because they feel excluded or overly controlled.

If you think about it, challenging behavior does work— to a certain degree. People do get more attention, higher levels of physical contact, or escape from work. But disruptive behavior (such as aggression) interferes with inclusion: It can endanger the person exhibiting it and others, upset staff, and contribute to a negative attitude toward people with disabilities.

Then get rid of the challenging behavior, right? Not so simple. The goal in positive behavioral support is not merely to "eliminate" but to understand the behavior's purpose. The individual can then learn to substitute a more positive behavior that achieves the same function. People learn better ways to make their feelings and needs known.

### First Steps

Just as in beginning any project, first obtain the necessary materials. In positive behavioral support, this involves making sure this approach is right for your family, gathering the people you need, having an idea of what you want, and finding out what purpose the challenging behavior serves.

**Ensuring fit with your values.** If you use this approach, you will have to be ready to forge ahead (rather than waiting for others to take the lead). You will also have to be prepared to custom-fit the plan to the person you are focusing on. This is not a "one size fits all" type of plan. And, instead of accepting whatever happens, you must be ready to actively solve problems, even anticipate them. This approach, too, focuses on rewarding good behavior, not punishing challenging behavior. Keep these values in mind when deciding whether this approach will work with your family.

**Putting together a collaborative team.** You probably could do this approach by yourself. But the odds for success would not be in your favor. A better way is to involve family, professionals, friends, and community members. Those sensitive to the culture, skills, routines, and values of the individual and family are ideal. Also, find those who can best

work with the child. Rapport—the ability to "connect"—can often be the miracle ingredient in behavioral changes.

**Creating a vision.** This approach is not an overnight, silver bullet cure. It takes time and effort. A vision of the ideal life for the individual with challenging behavior will fuel and help guide the journey. Typically, this vision begins with shared great expectations and incorporates to the maximum extent possible that individual's preferences for inclusive activities, relationships, and daily/weekly routines.

**Completing a functional assessment.** Challenging behaviors do not happen repeatedly without a good reason. Finding out "why" the behavior occurs is the key to positive behavioral support. Technically, the finding-out process is known as *functional assessment* and is a method of collecting and testing information. After you identify and clearly define the challenging behavior so that any one observing would know exactly what you are talking about, check to make sure you are on target about the probable purpose(s) of the behavior (for instance, to quit doing a difficult task). This can be done by some-one who has knowledge of the person or by technical experts. (Call The Family Connection at 1-800-854-4938 for reference to positive behavioral support experts.)

## STRATEGIES

Now, the next phase of positive behavioral support begins: Strategies to encourage behavioral changes. These include (in no particular order):

**Teaching new skills.** Challenging behavior often occurs because the individual does not know a more appropriate way to achieve a result. Determine necessary skills, then work together to encourage their development. Just as importantly, decide whether people working with the person who has the behavioral challenge need to learn new skills. If so, they, too, need to start acquiring new skills.

The new skill may successfully replace the behavior right from the start or it may take longer. When a flare-up does occur, ignore the behavior problem (in cases of physical injury, it may be impossible and unethical to ignore behavior) and introduce known methods that promote good behavior.

**Appreciating positive behavior.** Gathering information for the functional assessment caused you to focus on the individual. During that time you should have learned what the person views as rewards. Using those rewards when the person exhibits targeted positive behavior reinforces the likelihood that those behaviors will happen again. At the same time you concentrate on rewarding targeted behavior, remember to recognize other appropriate behavior and work toward encouraging the individual to have a positive identity.

**Altering environments.** If something in the person's environment influences the challenging behavior, it is logical to organize the environment for success. When adjusting the environment, focus, too, on what happens *between* challenging behavior incidents as well as on what happens *when* challenging behaviors occur. Arranging what happens during the day, when it happens, and how it happens decreases the chance of challenging behavior. The goal of positive behavioral support is not to avoid all places where challenging behavior might occur or simply to give in to all the individual's requests. Rather, the goal is to create a rich pattern of preferred activities and relationships that encourage desirable rather than undesirable behavior.

**Changing systems.** After working on the immediate environment, examine your system of services to see whether it is as responsive and personalized as possible. If not, do what you can to make it that way. Teachers can, for instance, request time for collaborative planning on behalf of the student with challenging behavior. A parent can explain positive support practices to school representatives. You may find that despite your efforts, the system is not changing directions or quickly enough for your family. In that situation, you may consider literally changing your system for another (e.g., changing schools).

## MONITORING IMPROVEMENT

As the support program develops, devise a recording system to find out what works and what doesn't. There will be fine tuning and changes along the way. If the initial plan is not working, take care to understand why it is not working. You can then use that information to design a new approach for the plan.

For example, a person can get bored doing the *same* tasks with the *same* people for the *same* rewards at the *same* time of day. Creating variation may solve this problem. The second roadblock is

that the people overseeing the positive behavioral support may get bored and less responsive to the person and his or her communication efforts. Taking a break and adding variety helps gets past this roadblock.

In some situations, you may find that in spite of your best efforts, the behavior was not affected. Ask yourself whether you gave the plan enough time, or if you or others criticized the person exhibiting the behavior or pled with the person to behave well. Both tactics can actually increase the challenging behavior. Positive behavioral support also may not be effective in self-injury that gives the child sensory stimulation (e.g., children may poke their own eyes to make a visual effect), or is in response to not enough or too much stimulation. Self-injury or aggressive behaviors also can be initiated or set off by underlying psychiatric conditions, such as depression, obsessive-compulsive disorders, or other disorders. Some scientists have even suggested that some self-injury may represent a type of addictive behavior that gives a "high."

When discussing positive behavioral support, the word "aversive" often is mentioned. The aversive method of behavioral change often uses quick application of discomfort or pain in response to challenging behavior. Sharp criticisms, slaps, offensive sounds or sprays, removal of a desired object, shocks, and isolation are aversive applications. In practice, aversives often fail to work. When they do work, their effectiveness diminishes over time and does not generalize to other settings. Besides making the person avoid the punisher, loss of self-esteem, potential harm, and other negative side effects, punishment does not teach desirable behavior or seek to examine "why" the behavior occurred in the first place. Often, the only thing a person learns is not to do the challenging behavior when the person applying the aversive is present.

### CRISIS ANTICIPATION

Also necessary from the start and throughout is a plan that anticipates dangerous situations. When someone has a behavioral challenge that results in property destruction, self-harm, or physical injuries, you can't be caught unaware. Devise a detailed, word-by-word script for how to respond to dangerous situations and distribute it to everyone in contact with the individual. Not only will this foresight increase the plan's effectiveness, it will provide support persons with a security blanket.

### END RESULTS

Positive behavioral support draws from teaching, systems design, behavior management, and social support to frame environments where people succeed and feel good about themselves. The results of this evolving approach support the independence, productivity, and inclusion of people with disabilities.

However, as one mom said, "Employing positive behavioral support is not like tightening a few nuts and bolts. It is about relationships as much as techniques. It always matters who does the intervention as much as what they do."

### RESOURCES

**Positive behavioral support: Including people with difficult behavior in the community**. Koegel, L. K., Koegel, R. L., & Dunlap, G. (Eds.). (1996), Baltimore: Brookes. $37.95. Call 800-638-3775 to order.

**Learning to listen.** Lovett, H. (1996). Baltimore: Brookes. $37.95. Call 800-638-3775 to order.

**Functional assessment of problem behaviors: A practical assessment guide.** 2nd edition. O'Neill, R. E., Horner, R. H., Albin, R. W., Sprague, J. R., Storey, K., & Newton, J. S. (1996). Pacific Grove, CA: Brooks/Cole. $31.95. Call 800-354-9706 to order.

**Guidelines: Effective behavioral support.** Pennsylvania Dept. of Education: Bureau of Special Education. Free. Call 717-523-1155, x213 to order.

**Using functional assessment to develop effective, individualized interventions for challenging behaviors.** Foster-Johnson, L., & Dunlap, G. (1993). *Teaching Exceptional Children, 25,* 44-50. To order, call 888-232-7733. Ask for JTEC253.

**Why does Samantha act that way?: Positive behavioral support leads to successful inclusion.** Family Connection staff, DeVault, G., Krug, C., & Fake, S. (1996, September). *Exceptional Parent, 26,* 43-47.

**Assessing problem behaviors.** (1996). Demchak, M., & Bossert, K. *Innovations, 4.* American Association on Mental Retardation, 444 N. Capitol St. NW, #846, Washington, DC 20001.

# PBS Research Findings—1985-1996

In the past, people typically tried to "punish" children exhibiting challenging behavior. That began to change in 1965 when psychologists studied a 9-year-old girl with schizophrenia who banged her head repeatedly on walls. When adults asked her to quit, she banged even more. When they ignored her behavior, she stopped banging. The psychologists discovered that banging was her way to attract attention.

Ten years later, researchers studied a boy who punched himself in the face (30 times a minute) during teaching sessions. When the teacher focused on another student, the boy quit punching. "Don't ask me to do this" turned out to be his message, and the study established the link between behavior and communication.

The link wasn't noticed earlier, said Dr. Ted Carr, University of New York-Stony Brook, because people used to think that behavior was "inside" a person and not related to environment. Another reason was that children with disabilities often were in institutions where few people tried to understand behavior.

Carr's recent positive behavioral research has concentrated on the research base itself. In his study of literature published from 1985-1996, Carr has concluded that positive behavioral support is not a fad and has evolved past its intervention focus to a concentration on the person's total environment.

"To date, there have been few synthesis reviews focused on PBS per se" wrote Carr, "because this approach did not gain momentum until the middle-to-late 1980s, after which there was an explosive growth in the number of research studies, conceptual papers and intervention manuals."

Carr and colleagues analyzed 109 research studies for demographics, assessment practices, intervention strategies, and results.

**Demographics.** Literature showed twice as many males as females in PBS studies. About half of participants had mental retardation (one-third functioning in the profound range, another third in the severe range). One-third displayed self-injury, one-quarter aggression, and the rest various challenging behaviors. Twice as many interventions occurred in disability-segregated schools, medical clinics, and other settings as did in homes, communities, or inclusive schools.

**Effectiveness.** Keeping in mind that the present goal of positive behavioral support is reduction, not necessarily elimination, of behavior, studies showed that if someone demonstrated challenging behavior 100 times in a row previously, after positive behavioral support 51 percent of people studied displayed the behavior only 10 times: A 90 percent reduction in over half of the studies.

The challenging behavior stopped completely in 26 percent of the studies. Neither age nor gender influenced the positive behavioral strategy's effectiveness.

The level of disability did influence success (e.g., mental retardation levels showed the following success percentages: mild, 45.1; moderate, 66.0; severe, 53.0; profound, 52.7.) The success percentage regarding behavior type showed positive behavioral support the most effective in self-injury, and tantrums; the least effective in property destruction.

**Applicability.** The trend has been moving away from a researcher-only strategy. Almost half of those doing the intervention were parents, teachers, and other nonresearchers.

**Literature responsiveness to nonresearchers.** The articles did not reflect significant interest in comprehensive lifestyle support (only 2.6 percent did so). Information on environment reorganization proved scant, and the information, in general, did not satisfy the desire of families, teachers, and others for long-term change. The vast majority of studies tracked regression for less than 12 months, not perhaps allowing enough monitoring as old habits often resurface. The research also did not meet the audience need for practicality and did not discuss support for people who carry the weight of caring for others.

Carr recommended more consumer participation in research studies. "The main message to researchers," Carr wrote, "is that we need a new applied science. For a truly applied science to develop, researchers need to address consumer needs more systematically and frequently."

Carr's review regarding the effectiveness of positive behavioral support was linked with the Beach Center study on stakeholder perspectives funded by Office of Special Education, U. S. Department of Education.

# The Family Connection

Families have long said that they need better access to research information on dealing with challenging behavior. Families also believe that research should be done on topics that families—not just researchers—consider to be priorities.

It's true, researchers often work on projects that have no *immediate* use for families. It's also no secret that often scientific research that does have practical use doesn't get used. One reason is because families don't have a good way to get that information. To help families get the information they need, The Family Connection was created.

Here's how The Family Connection works: Under the directorship of Rob Horner at the University of Oregon, the Rehabilitation Research and Training Center (RRTC) on Positive Behavioral Support conducts research on the causes of challenging behaviors and strategies for positive behavioral support.

Working with the RRTC on Positive Behavioral Support are top-notch researchers at the University of Oregon, California State University-Hayward, State University of New York-Stony Brook, University of South Florida, University of California at Santa Barbara, and the University Affiliated Program and Beach Center on Families and Disability at the University of Kansas. The Family Connection, located at the Beach Center, takes the researchers' work and gets it to families in as many ways as possible.

One way The Family Connection gets its information out is through its toll-free number. Parents, teachers, and others can call this number and discuss their child's behavior challenges or increasing opportunities for inclusion and get information that may help their family.

Currently the Family Connection receives about 500 calls a year. Of those calls, 75% are from families, 20% from teachers, and 5% from others interested in positive behavioral support.

Another way the Family Connection gets out information is by mailing the RRTC on Positive Behavioral Support's 265 item-material list, current research reports, review papers, and monographs produced by the RRTC.

The Family Connection also has a series of fact sheets that give parents the "bottom line" on various aspects of challenging behavior and helpful strategies. See a listing of these fact sheets on p.19.

The Family Connection was developed to connect families who have members with challenging behavior. By developing products in which families share stories about how they have successfully reduced challenging behavior and gained more positive lifestyles, The Family Connection can help other families "connect" who are seeking success in similar areas.

Denise Poston, Family Connection Assistant Director, said: "In our follow-up survey, parents say 'I learned not to get so upset about behavior,' 'I've learned new angles from which to look at behavior,' and 'I'm happy to know there's someone to call.'"

If Family Connection staff are unable to take the phone call, callers will be forwarded to voice mail. A staff member will then promptly return the call.

You can also write: The Family Connection/Beach Center on Families and Disability, University of Kansas, 3111 Haworth, Lawrence, KS 66045, 1-800-854-4938, dposton@dole. lsi.ukans.edu.

Research and Training Center on Positive Behavioral Support * Beach Center on Families and Disability * Kansas University Affiliated Program

- Richard W. Albin, Ph.D., Specialized Training Program, University of Oregon
- Doug Guess, Ed.D., Dept. of Special Education, University of Kansas
- Jacki L. Anderson, Ph.D., Dept. of Educational Psychology, California State University-Hayward
- Robert H. Horner, Ph.D., Specialized Training Program, University of Oregon
- Edward G. Carr, Ph.D., Dept. of Psychology, State University of New York-Stony Brook
- Robert L. Koegel, Ph.D, and Lynn K. Koegel, Ph.D., Graduate School of Education, University of California
- Glen Dunlap, Ph.D. Dept. of Child & Family Studies, University of South Florida
- Wayne Sailor, Ph.D., University Affiliated Program, University of Kansas
- Ann P. Turnbull, Ed.D., The Beach Center on Families and Disability, University of Kansas

## Rehabilitation Research and Training Center on Positive Behavioral Support

# National Training Network— State Training Team Coordinators

*State training team coordinators can assist you in reducing or eliminating challenging behavior in various ways, depending on the state. You may be put in contact with a trained team member in your area, have a member arrange a technical assistance visit, or attend an area scheduled training. Each state training team is organized, staffed, and operated differently. The sponsoring organization of each state (e.g., Department of Education, university, Department of Mental Retardation) also influences the team focus. If you do not see a team in your state, call the Family Connection (800-854-4938) or a team from a neighboring state.*

Judy Croswell
Arizona Dept. of Education
Exceptional Student Services
1535 W. Jefferson, 3rd Floor
Phoenix, AZ 85007
602-542-3184; 602-542-5404 (fax)

Katie Bishop
University of San Diego
School of Education
5998 Alcala Park
San Diego, CA 92110
619-260-4685; 619-260-6835 (fax)
kbishop@acusd.edu

Joe Schiappacasse
804 G Street
Salida, CO 81201
719-539-6499; 719-539-6499 (fax)
schiappa@chaffee.net

Charlan Corlies
Connecticut DMR
460 Capitol Ave.
Hartford, CT 06106
860-418-6133; 860-418-6003 (fax)

Hope Ellsworth
Community Services
Route 1, Box 1000
Georgetown, DE 19947
302-934-8031, x320;
302-934-6193 (fax)

Meme Eno-Hieneman
Div. Applied Research & Educ.
(MHC 1-250a)
University of South Florida
13301 Bruce B. Downs Blvd.
Tampa, FL 33612
813-974-6440; 813-974-6115 (fax)
eno@hal.fmhi.usf.edu

Cathy Pratt
Institute for Study of Dev. Disabilities
Indiana University
2853 E. 10th St.
Bloomington, IN 47408
812-855-6508; 812-855-9630
prattc@indiana.edu

Mike Ruef
Beach Center on
Families and Disability
University of Kansas
3111 Haworth
Lawrence, KS 66045
785-864-0727; 785-864-7605 (fax)
mike@dole.lsi.ukans.edu

Shawn Fleming
223 Peabody Hall
Louisiana State University
Baton Rouge, LA 70803
504-388-8767; 504-334-1045 (fax)
fleming@asterix.ednet.lsu.edu

Richard S. Amado
Community Support Services
1195 Juno Ave.
St. Paul, MN 55116
612-698-6040; 612-698-5666 (fax)
amado002@gold.tc.umn.edu

Cori Brown
UMKC-Institute for Human Development
2220 Holmes Rd.
Kansas City, MO 64108
816-235-1764; 816-235-1762 (fax)
cori221@aol.com

Jody Hoffman
OMRDD
44 Holland Ave.
Albany, NY 12229
518-473-1190; 518-473-4490 (fax)

David Otterstrom
Oklahoma State DOE
440 S. Houston, #202
Tulsa, OK 74127
918-581-2532; 918-581-2760 (fax)

Rick Albin
Specialized Training Program
1235 University of Oregon
Eugene, OR 97403
541-346-2464; 541-346-5517 (fax)
rick_albin@ccmail.uoregon.edu

Tim Knoster
CSIU
P. O. Box 213
Lewisburg, PA 17837
717-523-1155, x213;
717-524-7104 (fax)

Melissa Brown
LRE/LIFE Project
UT Conf. Center., Suite 312
Knoxville, TN 37996-4135
423-974-2760; 423-974-3857 (fax)

Gigi DeVault
P. O. Box 807
Graham, WA 98338
253-536-2494

Don Kincaid
UACDD/WVU
Research and Office Park
955 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692; 304-293-7294 (fax)
kincaid@wvnvm.wvnet.edu

Carol Schall
V. I. D. D.
301 W. Franklin St.
P. O. Box 843020
Richmond, VA 24015
804-828-8246; 804-828-0042 (fax)

# Stakeholder Perspectives

In the Beach Center study *Perspectives of Six Stakeholder Groups on the Challenging Behavior of Individuals with Mental Retardation and/or Autism* resear-chers, Mike Ruef and other Beach Center staff held 12 focus groups to better understand stakeholder perspectives and experiences relating to challenging behavior. From the analyzed data, the following are some significant findings.

**Current experiences.** *Administrators and policy makers* described little direct contact with challenging behavior and noted frustrations in policy development, societal devaluation of individuals with challenging behavior, and the current movement to remove students with challenging behavior from neighborhood schools to separate alternative schools.

*Families* criticized the lack of comprehensive, coordinated, ongoing support from professionals. One mother whose son was severely self-injurious said, "He was thrown out of school. I was pretty much one-on-one alone with him for a couple of months, mainly in his room trying to keep him from hurting himself. I had to quit my job because of the intensity of the care he needed." They also described the physical and emotional impact challenging behavior had on them.

*Friends* said they had difficulty coping with their own and others' reactions to challenging behavior and described various communication breakdowns. *Individuals with disabilities* mentioned strong environmental dislikes and limitations placed on their personal freedom by support agencies

**Stakeholder Views on Challenging Behavior of Persons With Mental Retardation or Autism**
**Who:** Administrators/policy makers, families, friends, individuals with challenging behavior and mental retardation or autism, researchers, and teachers
**What:** Twelve focus groups on current experiences, solutions, and information.
**How:** Qualitative analysis of participant comments (content data analysis of focus group transcripts)
**When:** 1997
**Where:** Beach Center on Families and Disability
**Why:** To develop a better understanding of stakeholder perspectives and experiences relating to challenging behavior.
**Study results:** Findings point to the importance of (a) establishing trusting relationships between givers and receivers of support and of (b) creating environments woven with enabling supports.

*Researchers* talked about division in the research community regarding aversive procedures. They also highlighted that behavioral interventions require training and planning and said that many inadequately trained persons designed and supervised poorly prepared behavioral management plans.

*Teachers* voiced confusion over behavior policies and frustration with overall lack of behavior training and classroom support.

**Practical positive solutions.** *Administrators and policy makers* recommended more training for teachers, use of best practices, more resources, and better use of existing resources. Some suggested that the answer to challenging behavior lies in restructuring the school system for all children. *Families* suggested positive support strategies, collaboration, committed people, friendship building, research and training, and nontraditional strategies.

*Friends* believed the secret to lessening behavioral challenges lay in developing relationships with and gaining information about the individual through other "veteran" friends.

*Teachers* recommended increased support from administration, collaboration, improved pre- and in-service training (e.g., positive behavioral support and peer mentoring).

"Respect the individual," said one English teacher at a suburban high school on the West Coast. "Do that," she said, and "you've got a head start on eliminating challenging behavior."

One student, the teacher related, had a problem with literally walking into a classroom. When asked what would eliminate the problem, the student said "singing."

The next day the student asked others in the class to sing when he walked in the door. They did. Since then, there have been no problem behaviors from that student in her classroom.

*Researchers* desired increased training for others in behavioral technology and to conduct studies that included intervention phases

**"Respect the individual," said one English teacher at a suburban high school on the West Coast. "Do that," she said and "you have got a head start on eliminating challenging behavior."**

and quality of life measurements.

*Individuals with challenging behavior* wanted improved quality of life, individualized outside support, and desired environmental adaption.

**Helpful behavior strategy informational products.** Study results pointed to the importance of receiving condensed behavioral support information on both the awareness and skill levels and to the continued gap between research and practice in spite of extensive research on effective dissemination strategies and techniques.

Stakeholder groups divided into two categories: (a) Those who discussed the informational needs of other stakeholder groups, and (b) those who discussed their own needs.

*Administrators and policy makers* made no reference to their own needs. Instead, they directed their attention to teachers, whom they felt were undertrained and needed more information.

*Families,* while noting their own lack of information, suggested that professionals should be much better informed than they currently are and should serve as sources of information for families. Families desired information on a variety of very specific subjects, including diet, echolalia, facilitated communication, functional analysis, and medications.

Products that *friends* found worthwhile were a relationship profile that had a variety of people providing information about the person (likes, dislikes, etc.) and a scripted crisis plan, which also provides consistency.

*Teachers* mentioned the value of behavior specific information including step-by-step directions on what to do as well as lots of examples.

*Families, friends, individuals with disabilities,* and *teachers* all ranked information from like or trusted stakeholders as the most valuable.

*Individuals with disabilities* also stressed the importance of receiving information from persons they trusted and didn't mention specific media so much as the manner in which they liked to receive information—in a way that complemented their individual learning styles with role playing a commonly mentioned strategy. *Teachers* liked the idea of sharing sessions where teachers could get together to trade ideas, problems, and solutions on a regular basis.

**Written materials.** Participants were less than enthusiastic when asked about written materials. They found journal articles ineffective (too long and complicated) and wanted short, entertaining, pleasantly formatted information.

A better approach, researchers agreed, was to have a professional writer work in collaboration with a behavioral support expert to create a popular book. Researchers also mentioned "how to" booklets and news coverage. Partnerships with the media, said some researchers had its disadvantages. "The media is the dragon's tail. . .you start playing with it, you never know what the outcome is going to be. They're not out there to just get your message across. They're there to entertain and to get, sometimes to stimulate, controversy, and it can be dangerous."

Study participants continued to stress the need for concise, easy-to-understand information. In summarizing the need for simplicity, one parent said, "We heard Robert Horner who has a way of presenting information that makes you go 'My goodness, why didn't I think of that.' It's very humorous and very light."

**Stakeholder understanding.** About the study Ruef wrote: "The unique and potentially valuable contribution of this study lay in the convergence of diverging perspectives on challenging behavior.

"In analyzing and reporting the findings, its was easy to become lost in details and lose sight of the overall study implications.

"If challenged, however, to present the most relevant implications in the briefest posible way, I would rely on a quotation by Stephen Covey, 'Seek first to understand, then to be understood.'

"The difficulty of putting this statement into practice was reflected by the focus group data.

"It became clear that no one stakeholder group had a good understanding of the issues other groups considered important.

"Although some groups were more aligned and some groups less aligned with each other, the most important finding of this study is that not enough understanding has occured between and among stakeholder groups."

# Challenging Behavior and Inclusion

Challenging behavior can be a significant source of stress for family members who lack support. Children exhibiting these behaviors also face a high risk of exclusion from others around them, including their own families. Community inclusion would be easier achievable, some say, if more researchers addressed family issues and families had easy access to state-of-the-art research.

However, the tendency is for researchers to develop studies from their point of view rather than the perspectives of families and service providers.

To learn more about family needs regarding behavior, Beach Center researchers developed The Information Profile on Challenging Behavior and Inclusion survey.

**Who:** 86 parents who had children with disabilities exhibiting various degrees of challenging behavior
**What:** Study examining family perspectives on problem behavior
**When:** 1994
**Where:** Beach Center on Families and Disability, The University of Kansas
**How:** 79-item mail survey based on previous qualitative study
**Relevant finding:** Parents distinguished dangerous from difficult behavior and have a strong interest in learning ways to help their children with disabilities develop friendships.

**Research participants.** Eighty-six families completed and returned the survey. The majority were mothers aged 30-49 (85.7%); had children ages 3-11 (65.4%); and reported that their children had autism (60.5%), mental retardation (31.4%); learning disability (18.6%), emotional disability (12.8%), physical disability (10.5%), and other (36%).

The 81-item survey addressed challenging behavior, school supports and services, family relationships, family responsibilities, supports and services for adulthood, dangerous behavior, difficult behavior, and demographic information.

For each survey section, participants were asked to indicate whether or not they would like information. They were asked to priortize their top three informational needs relating to the section. Descriptive information was also collected on the nature of the challenging behavior exhibited by the participants' children.

**Principal findings.** All parents expressed a strong interest in receiving information on encouraging and supporting friendship and on minimizing one's own and others' fear and worry about challenging behavior.

They also wanted to know how (1) the brain processes information that may contribute to challenging behavior, (2) challenging behavior is an attempt to communicate needs and frustration, and (3) to plan ahead for change to new environments.

Results expanded the definition of challenging behavior as "dangerous" (self-injurious, physical aggressiveness, property destruction, pica) determined in an earlier Beach Center study. Parents added "difficult" behavior (tantrums, public masturbation, gas passing, excessive displays of affection, conversation interruption) to the definition of challenging behavior.

"When I am around him it is constant noise. He talks or squawks. By afternoon I am frazzled" was a comment describing difficult behavior. Dangerous behavior was exemplified by the statement "He broke the windshield of the car recently."

The vast majority of parents reported their children as having exhibited one or more episodes of dangerous and/or difficult behavior in recent years.

Further, parents said these behaviors made them experience worry (87%), fear (60%), annoyance (88%), and embarrassment (78%).

As most participants were well educated, white mothers of children aged 3-11, results should not be generalized to other audiences not adequately represented in the study. Results did, however, suggest a number of additional possibilities for research. Among these would be an analysis of stakeholder attitudes toward information and research on groups (e.g., fathers, other cultural groups) underrepresented in the study. Further information on this study can be found in:

Turnbull, A. P., & Ruef, M. (1996). Family perspectives on problem behavior. *Mental Retardation 34*(5), 280-292.

Turnbull, A. P., & Ruef, M. (1997). Family perspectives on inclusive lifestyle issues for individuals with problem behavior. *Exceptional Children, 63*(2), 211-227.

# Model Statute on Positive Behavioral Support

No better time for a proposed legislative effort regarding positive behavioral support has ever existed. This is because the reauthorized Individuals with Disabilities Education Act (IDEA) contains two specific provisions related to positive behavioral support.

One provision requires students' Individualized Education Program (IEP) teams (which now must include the students' parents) to consider using positive behavioral support whenever a student's behavior gets in the way of that student's own ability to learn or the ability of other students to learn.

The other provision requires the IEP team to assure, within 10 days after the student has been disciplined, that the student will receive a functional assessment of behavior and a behavioral intervention plan (if the student does not already have one).

If there is a plan in place, the IEP team will review and revise it if warranted.

In response, Rud Turnbull and Ann Turnbull have developed a model statute and technical assistance guidelines that state and local educational agencies can use to put into place these discipline-related IDEA provisions.

Research has shown that a whole-school approach using positive behavioral support encourages appropriate behaviors by all students. Therefore, this technique ensures both a free appropriate public education in the least restrictive environment for students with disabilities and a school-wide environment safe and conducive to learning by all students.

Based on Dr. Ted Carr's comprehensive review of research on positive behavioral support (see p. 4) and formed by a participatory action research team of advocates, parents, educators, and researchers, this model:

- Defines positive behavioral support to include educational systems change, alteration of the immediate educational environment, instruction of the student and others in the student's school and community, and reinforcement of the student's appropriate behaviors.
- Demands that positive behavioral support should be provided whenever a student's behavioral impedes learning.
- Defines impeding behavior as behaviors that are aggressive, self-injurious, destructive of property; manifestations of depression, passivity or internalization; obsessive, compulsive stereotypical, irresistible impulses, and could cause suspension or expulsion; and require frequent use of positive behavioral support interventions and support.
- Provides for a positive behavioral support plan based on functional assessment, to be part of the student's IEP.
- Requires schools to use only positive interventions and prohibits aversive procedures.
- Restricts schools from using physical restraints except under specified conditions and allows only a few "emergency" exceptions to positive interventions.
- Requires all general and special educators to be trained in positive behavioral support, makes the training available to parents, and specifies how the training will be provided and by whom.
- Describes the evaluation, monitoring, reporting, and systems-change that state educational agencies must use to oversee what local educational agencies do, with respect to discipline and positive behavioral support.
- Describes and requires school to use only best practices of positive behavioral support.
- Rejects the idea that, for schools to be safe, the rights of students with challenging behavior must be balanced against the interests of other students; instead, it asserts that if positive behavioral support is provided to all students with and without disabilities, schools will be safe for all students.

This model, based partially on state statutes from California, Illinois, Pennsylvania, and Vermont, has been distributed to state directors of special education for further input.

Those wanting to comment on the statute should contact Rud Turnbull (Rud@Dole.lsi. ukans. edu at the Beach Center address. For a full copy of the statute, see the Beach Center web page (www. lsi.ukams.edu/beach/ beachhp. htm) or order a copy on p. 19 of this newsletter.

# Family Stories

## Sam's Turnaround

Samantha, 10, likes to write poetry, use computers, and listen to music. The principal describes her as a model student. Last year no one would have said Samantha was a model student.

She scratched, hit, bit, damaged equipment, ran out of classrooms, and pulled her educational assistant's long, blonde hair. Sam's parents lived on the edge, always waiting for "the phone call" from school.

This third grader with autism and moderate speech disabilities who did not belong, became the fourth-grader genuinely welcomed at school thanks to a strategy known as positive behavioral support.

Traditionally, people did not ask why inappropriate behavior occurred. They just wanted to fix a situation. If they had spent time investigating "why," they might have realized the behavior had a purpose.

In Samantha's situation, outbursts were her methods to communicate. When she threw an object, it was her request for attention. Pulling hair got her out of work that she did not want to do.

Find the reason for the behavior, then teach a more acceptable behavior. That's what a team of people who best knew Sam did. In her situation, like most others, contributing complex factors first had to be understood and pinpointed in a functional assessment.

In Samantha's functional assessment, trained specialists from the University of Washington at Seattle talked with people in Samantha's life and directly observed her. They determined what happened before, during, and after the outburst.

When the team had a detailed description of the challenging behavior, members made predictions when the behavior would most likely (and least likely) occur. Then they tested their ideas to see whether their hunches were on target. Samantha's functional assessment showed that she used her outbursts to avoid difficult tasks, obtain attention, and to express her frustration at not being able to make choices or have some control in her environment. Lack of sleep and changes in routine also set off her outbursts.

Once they knew Sam's triggers and the reasons for her behavior, the support team made changes for her life that gave her day greater predictability, more choices (but not so many that would overwhelm her), fewer instructions, and added relevance to her school work.

Changes happened at home, too. After Samantha behaved better, her parents, school staff, and others who cared about Samantha got together and discussed the "ideal" life for Sam.

All thought that making friends, spending more time in the regular classroom rather than the resource room, and medications with fewer side effects were part of that ideal life.

Soon Sam was in the school band, Girl Scouts, an arts program, and a church group. This exposure helped Sam's social skills, but she still got frustrated easily when she did not get her way.

Sam's parents and school staff taught her to recognize anger through picture cards. They also encouraged Samantha to talk about her feelings and go to a quiet place for relaxation when she got mad.

To help make these new changes stick, Sam's appropriate behaviors were continually rewarded. To make rewards ones that Sam really liked, the team asked those who knew Sam for suggestions and they asked Sam herself. Samantha had very definite ideas about things that she liked!

Ice cream ranked at the top, followed closely by "slurpees," a drink from a local store; Barbie doll items; and McDonald's restaurant food. In time, she did not need as many material rewards. But she always received continual praise for her desirable behavior. Bit by bit, Samantha's new life took form. Yet, the course did not necessarily run smoothly. Since they never knew exactly when Samantha might have an outburst, her support team prepared advance plans to deal with possible relapses.

Samantha's behavior changed relatively quickly. But old habits often resurfaced. Checking weekly (even daily) for progress, such as counting the number of times a behavior does or does not occur, decreases in medicine dosages, writing in a daily log, and other methods, helped keep the plan working.

*If you would like to know more about Samantha and her story, see the videotape about Samantha, available for $30.00 prepaid (price includes shipping and handling) from the Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045.*

## Success in her Pocket

Ashley, 8, diagnosed with autism at age 2, can use 5-word sentences, plays with dolls, and likes getting dressed up. Ashley's's absolutely favorite thing to do is eat. She is always hungry. Her absolute most unfavorite thing to do used to be going to sleep. She made herself and her family miserable when it came time to sleep.

Her parents Gary and Sharleen wanted to solve the family's problem. The answer came at a Parks and Recreation-sponsored workshop that Sharleen attended.

Dr. Rob Horner discussed positive behavioral support, which made sense to Sharleen. When Horner recommended a specialist for their family, Gary and Sharleen leaped at the chance to learn more about positive behavioral support.

The consultant came to their house. He talked about their family, values, schedules, stresses, and strengths. Then he described positive behavioral support and its backbone—learning all you can about the person with the challenging behavior.

"The plan's goal is to prevent challenging behaviors by making them ineffective, inefficient, or unnecessary," Sharleen said. "The strategy was to teach new appropriate skills and keep from strengthening her challenging behaviors."

Gary and Sharleen worked with the consultant on a functional assessment to figure out why Ashley did the things she did.

They first described Ashley's bedtime routine. The routine started with her parents putting on her pajamas (*Ashley didn't want to go to bed, so she sure didn't want to help put on her pajamas*). Ashley's had a snack (*remember, she's always hungry*), then her parents fought with her to use the bathroom.

They didn't bother with teeth brushing, because they used all their energies on the "potty fight." Between 9-9:30, she was tucked in bed, encouraged to say a prayer, the lights went off, and her parents shut the door to keep out noise.

Not long after, the family could hear toys thrown on the floor. Then the wall kicking started, followed by screaming and crying. If no one checked in, Ashley would start banging her forehead on furniture. She'd scratch and pinch herself.

What started the behavior eruption? That was easy to answer: Going to bed at night with the light off and door closed.

The tricky question was: "Why was Ashley doing all this? Why was it getting worse?"

"Our response to her problem behaviors was the key," Sharleen said. "When she'd cry, we'd try to lovingly offer her bananas or popcorn in case she was hungry. One of us would cuddle up with her on her bed to comfort her. We would stay in there till midnight, even later.

"If we did everything we could, we let her 'cry it out.' We didn't want to pay off her tantrums. What Ashley's got out of her behaviors was attention (cuddles, talking, physical contact) and food."

Next, Gary and Sharleen had to think about what they wanted their evenings to be. That was harder than they thought. Their home life had just evolved from one phase to another without planning. When they started planning, Gary and Sharleen had to be specific about what they wanted Ashley to do, and in what order, who would do what to help her, and what help they could use—just like a recipe for a cake.

After much thought, they decided that she should be asleep by 8:30 p.m. They both wanted to get her to bed, have a small snack, keep a few toys in bed that could keep her entertained if she didn't fall asleep immediately.

"This is how we saw it: She puts on her own pajamas. She'd have a snack with a small amount of melatonin it, she would potty, brush her teeth, wash, then come out for a hug. Ashley would say 'good night,' pick a parent to tuck her in, pray, then go to sleep, and stay asleep."

Ashley now gets ready for bed in a climate conducive to falling asleep. She has yogurt or sugar-free ice cream with a small melatonin dose and is offered a tiny doll cup of herbal tea.

While she eats, her brother and sister are put to bed (where they can read), and her parents don't do anything that creates excess noise. During her routine, her parents use embedded reinforcers, such as a special watermelon soap when she washes her hands after using the toilet.

"We also use positive contingencies, upfront or at the first glimmer of resistance. One might be 'If you wash your hands really good, you can use Mommy's hand cream.' Things like that. These are not bribes. A bribe would be stop crying and I'll give you a Cheet-o. As soon as the Cheet-o is gone, the child cries again in hope of getting another."

Her tasks are done in an unhurried manner with praise and hugs. When she is tucked in, music plays softly in her room, so softly that she has to be quiet to hear it. "It seemed to me that if close physical contact was what she was tan-

trumming to get, why not give it her proactively?," Sharleen said. "When she is in her jammies and hygiene tasks are done, she knows she can sit in my lap with her favorite blanket for 10-15 minutes.

"This has become my favorite time of the day. During this time we talk about how nice sleep is and what tomorrow will bring. In the beginning, I had to stress that there would be a tomorrow. That the sun tucks away in bed, that it would wake up and so would she. I had no idea she had a fear about tomorrow not coming."

When they first began the routine, Ashley was told her parents would check on her in two minutes. They did, praised her, and told her they would be in again in two minutes.

They extended the checkup to five minutes, then 10 minutes, as Ashley increased her endurance. After a while, the check-ups—Ashley's safety signals—became unnecessary.

Teaching Ashley to ask for attention has also helped. "What we practice with Ashley is 'I need you.' About one week after we began this routine, she was in bed, and I was picking up the family room. I saw her across the room and I thought I'd drop my drawers when I heard her whisper 'I need you.' Baby, I was there."

No plan is foolproof. When Ashley does cry, her parents say "What do you need to say?" and she'll reply, "I need you," which her parents request her to repeat three times.

The point is to make Ashley understand that it would have been easier if she had asked for help. If Ashley's behavior escalates in spite of what her parents do, they have an emergency procedure. They put her in a nonaggressive hold and try to make it clear that they can't help unless she asks for it appropriately. "Then, we will move heaven and earth to give her what she wants, or make a compromise.

"The plan has been extremely successful. We rarely have a problem and she sleeps well each night. Her daytime behaviors are better, and she has a firmer foundation on which to progress.

"Another beauty to the right plan is that you can generalize to other areas and routines. In our case the car, baths, and we've even had success in the classroom.

"Now, with success in her pocket, Ashley feels confident to progress. Her language is up, her cooperation is easier to obtain, and she's a happier child."

*This story came from a personal letter to the Beach Center.*

## Making the Connection

Alan, 15, has mild cerebral palsy and functions in the moderate range of mental retardation. Alan and his family had a problem: Alan's tantrums—up to five times a day, mostly at school. He struck out at others, shook his head, hit things, and screamed.

After spending time with Alan and talking with people who knew Alan best, researchers found that he most often had problem behavior when he had to do tasks that he found too hard to do without teacher help. Once the researchers understood the cause, they devised a treatment plan.

First, they gave Alan a task to do, one that his teacher said he could usually do (such as stapling) at least 75 percent of the time. If Alan looked like he was having difficulty, the teacher helped by showing him how to do the task and giving him encouragement. Once Alan finished the task, the teacher praised him. Alan also received praise and assistance, if he asked for help (which he had been taught to do in the past).

Next, the researchers gave Alan a task that his teacher said he needed help with to finish. When Alan asked for help, he was told to do the best that he could.

If Alan "hit out" without hitting anyone or thing, the teacher (a) physically blocked his hit, (b) gave him a mild reprimand, and (c) told him to do the task. If Alan verbally asked for help, the teacher helped him. The teacher worked with Alan to communicate his needs instead of Alan's usual method of throwing a tantrum.

The following step was to teach Alan to say "help" each time he came to the part of the task he found difficult. Researchers worked with Alan in 10-minute sessions until he could do a task with 90% accuracy without any prompting in two sessions. Follow-up sessions were conducted to make sure Alan remembered to ask for help. After Alan learned to say "Help, please," a noticeable reduction in his tantrums was observed by all.

*The story of Alan was in a journal article by Jeffrey Sprague and Robert Horner called "Covariation Within Functional Response Classes: Implication for Treatment Severe Problem Behavior." Call the Family Connection at 1-800-854-4938 for more information.*

## Harness Is Gone

*Wrote one mom:*

In the last few years, we have had several deaths in the family. These deaths gave me a growing realization that I had to take not

just responsibility for the quality of my and my son's life, but that I had to take control and accept consequences to a much greater degree than I had been. Time runs out.

Four years ago, my son took off the seat belt he was wearing, left his seat, and physically attacked the aide on his special ed bus. Since then, he has worn a four-point harness as part of a written plan designed by our school district's "behavioral specialist."

Because the bus aides are afraid of Matt and refuse to put the harness on him, I had been boarding the bus in the morning and afternoon to do so. I suspected that the harness was left on him when he arrived at school and he walked from the bus to his classroom. I believed the same thing happened in reverse at the end of the school day, too.

A few months ago, I said to myself, "Why am I taking part in something so humiliating? Something that alienates him?" For years, I had been waiting for someone else to take care of this problem.

I also had to ask myself, "Just what is Matt supposed to do to get out of this harness?" It all came to a head one afternoon when I was informed that even the classroom aide was afraid to put the harness on him at school, thereby putting the problem into the laps of the bus aides who had already refused to do it. Apparently I was the only one without a contract defining my duties. The time had come.

Phone calls flew back and forth between my house and the school. I no longer was going to enable a bad situation to go on. I am not particularly proud of this, but the next morning when the bus driver refused to open the bus door unless I promised to board and harness Matt, I stood in the yard shouting at her.

As punishment for my refusal to cooperate with the plan, and because four years of harnessing did not teach Matt how to ride a bus appropriately, we were denied bus service. More phone calls ensued.

The next day a cab, paid for by the school district, arrived to take my son back and forth to school. He is the only passenger, but he was the only passenger on the special ed bus.

The cab driver, thankfully, has been deprived of any specialized disability training and does what he does for Matt just as he would for any other passenger. Additionally, he gives me notice when Matt is scheduled for a half-day, something the school still doesn't do. He has an interest in Matt and our family. As for Matt, he uses his seat belt and stays seated the entire ride. There hasn't been a single problem in months. The harness is gone.

*This story is from New Stories for a New Day, a collection of turning-point stories from members of the Autism National Committee (AUTCOM). Founded in 1990, AUTCOM promotes the use of positive, respectful approaches for teaching for all person with autism, pervasive developmental disorder, and related communication disabilities. AUTCOM objects to programs that disregard the skills, preferences, and basic human needs of people. Ann Turnbull, Beach Center Co-Director, is an AUTCOM board member and New Stories ($4.50) can be purchased from the Beach Center.*

## Hearing the Message

*Another mother tells her family story:* Our son was having multiple behavior problems. The worst was the screaming. Everyone in his segregated class was nonverbal. In fact, two students communicated only by screams. I observed my own son scream 50 times in ten minutes one day at school. That high-pitched scream. We had to figure out why he was doing this and what to do about his behavior.

We got a team of people together to do this massive brainstorming. Because he screamed in hallways to hear the echoes, we decided to give him gum to chew.

He also screamed when the bells went off because of his sensitive hearing. To remedy that, we asked his peers to precoach him before a bell went off.

He screamed, too, to escape fine motor tasks, so we changed the tasks. The other reason he screamed was when he was sick and had ear infections, so we taught him to communicate his pain.

It took a year. At first he was down to 1-10 screams a day. After three months, it was 0-1 times a day. Twice this past year, he has woken up and said, "My ears hurt. Need a doctor."

He continues to make progress. Now he is in general education classes half the day and takes community instruction. He has already surpassed all of our dreams. We have had to create new ones.

*This story appeared in the Beach Center publication What Research Says: Understanding Challenging Behavior and Teaching New Skills.*

# Functional Assessment of Behavior

The functional assessment is a foundation of behavioral support. It is not a medical diagnosis that comes with a prepackaged plan. Instead, the functional assessment's results let caregivers design an environment that "works" for people with communication and behavioral challenges. The person with the challenges and those who best know the person collaborate with a person trained in behavioral analysis. Together, they plan how to meet the challenges of problem behavior.

Functional assessment methods look at the behavioral support needs of people who exhibit the full range of challenging behaviors, such as self-injury, hitting and biting, violent and aggressive attacks, property destruction, and disruptive behaviors (e.g., screaming or tantrums).

Those who exhibit challenging behaviors may be labeled as having a developmental disability, autism, mentally retardation, mental illness, emotional or behavioral disorder, traumatic brain injury or may carry no formal diagnostic labels at all. These individuals vary greatly in their overall support needs and ability to communicate and participate in their own behavioral support.

Information about when, where, and why challenging behavior occurs builds effective, efficient behavioral support, because unplanned strategies can make behaviors worse. Also functional assessments are mandated by the Individuals With Disabilities Education Act for use by Individualized Education Plan (IEP) teams addressing behavioral concerns. Many states, too, have laws or regulations stipulating the need for a functional assessment before permitting significant behavioral interventions. The observations may find out that behavior strategies aren't necessary. Instead, the behaviors may have a medical cause. Allergies, infections, menstrual cycle effects, toothaches, chronic constipation and other medical conditions may bring on challenging behaviors. Medication also can influence behavior.

*A functional assessment:*

- Clearly describes the challenging behaviors, including behaviors that occur together
- Identifies the events, times, and situations that predict when the challenging behaviors *will* and *will not* occur across the range of daily routines
- Identifies the consequences that maintain the challenging behaviors (what the person "gets out" of the behaviors, e.g., attention, escape, preferred items)
- Develops one or more summary statements or hypotheses that describe specific behaviors, specific types of situations in which they occur, and the reinforcers that maintain the behaviors in that situation
- Collects directly observed data that support these summary statements

A functional assessment can be done in many ways and at different precision levels depending on the behavior severity. A person who has observed undesirable behavior in different situations and concluded that "she does that because. . ." or "he does that in order to. . ." has also developed a summary statement about the variable-influencing behavior.

A complete assessment allows confident prediction of the conditions in which the challenging behavior is likely to occur or not occur and when there is agreement about the consequences that perpetuate the challenging behavior.

*Functional assessment methods fall into three general strategies:*

**Information gathering** (interviews and rating scales). This method involves talking to the individual and to those who know the individual best. It also consists of formal interviews, questionnaires, and rating scales to identify which events in an environment are linked to the specific problem behavior.

Questions to answer include: What challenging behaviors cause concern? What events or physical conditions occur before the behavior that increase the behavior's predictability? What result appears to motivate or maintain the challenging behavior? What appropriate behaviors could produce the same result? What can be learned from previous behavioral support efforts about strategies that are ineffective, partially effective, or effective for only a short time?

**Direct observation.** Teachers, direct support staff, and/or family members who already work or live with the person observe the person having challenging behaviors in natural conditions over an extended period. The observations must not interfere with normal daily environments. In most cases, observers record when a problem behavior occurs, what happened just before the behavior, what happened after, and their perception as to the function of the behavior. When an observer collects 10-15 instances of the behavior, he or she might discover where a pattern exists.

**Functional analysis manipulations.** Taking the assessment one step further is the functional analysis. In this process, a behavior analyst systematically changes potential controlling factors (consequences, structural variables, i.e., task difficulty or length) to observe effects on a person's behavior.

These determinations involve creating situations that will reduce, eliminate, or provoke the challenging behavior to test whether the hypothesis is correct. Functional analysis—expensive in time and energy—may be the only way, in some cases, to ensure an adequate assessment. It is the only approach that clearly demonstrates relations between environmental events and challenging behaviors. To support the functional assessment, also consider measuring activity patterns (the variety and degree of community integration and relationships).



*Behavioral support must be conducted with the dignity of the person as a primary concern.*

*The objective of functional assessment is not just to define and eliminate undesirable behavior but also to understand the structure and function of behavior to teach and promote effective alternatives.*

*Functional assessment is a process for looking at relationships between behavior and the environment. It is not simply a review of the person with challenging behaviors.*

For more information on positive behavioral support, call the Family Connection at 1-800-854-4938 and ask for our free fact sheets, a listing of related articles, or answers to questions.

This is a product of The Family Connection. The Family Connection, under the directorship of Rob Horner (University of Oregon), the Research and Training Center (RRTC) on Positive Behavioral Support, conducts research on the causes of challenging behaviors and strategies for support. Working with the RRTC are the University of Oregon, California State University, State University of New York at Stony Brook, University of South Florida, University of California at Santa Barbara, and the University Affiliated Program and the Beach Center on Families and Disability at the University of Kansas. The Beach Center (3111 Haworth, University of Kansas, Lawrence, KS 66045, 785-864-7600) takes the researchers' work and gets it to families in as many ways as possible.

This is a program and publication funded by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education. Opinions contained in this publication are those of the grantee and do not necessarily reflect those of the U.S. Department of Education.

Adapted with permission from O'Neil, R. E., Horner, R. H., Albin, R. W., Sprague, J. R., Storey, K., & Newton, N. S. (1997). *Functional assessment and program development for problem behavior: A practical handbook.* Pacific Grove, CA: Brooks/Cole.

# ❖Ten Ways to❖
# Support a Person With Challenging Behavior

*In The Community Journal, David Pitonyak wrote that supporting a person with challenging behavior starts with knowing the person, not just looking at the person as someone needing "fixing." Imagine living the person's life, Pitonyak wrote, and view the following list as first steps to building a more effective behavioral plan.*

**1. Get to know the person.** Seems obvious, doesn't it? However, often people trying to eliminate unwanted behavior don't know the person behind the behavior. To learn more about the person with challenging behavior, spend time with that person in comfortable places at times the person prefers.

**2. Remember that all behavior is meaningful.** Challenging behavior sends the message of needs not being met. The behavior could mean, "I'm lonely," "I'm bored," "I have no power," "I don't feel safe," "I don't feel valued," "I have physical pain," or other needs. A single behavior, too, can reflect several needs. Keep in mind that the behavior often has something to do with what the person is asked to do and who is doing the asking. After a while, you should see a pattern to the behavior.

**3. Help the person develop a support plan.** Include the person with the challenging behavior in any planning and look at improving the person's whole life—relationships, community participation, choices, skill development, and contributions.

**4. Develop a support plan for the supporters.** Create a supportive environment for everyone concerned. Care givers need care and support, too.

**5. Don't assume anything.** Diagnostic labels and past performance often cause people to assume incorrectly. Speak to the person even if you're not sure whether the person understands. Never speak about the person with a disability as if that person wasn't present. It isn't polite, nor is it supportive.

**6. Relationships make all the difference.** Many people with disabilities live in extraordinary isolation. Some depend entirely on their family or paid staff for their social relationships. To overcome this isolation, brainstorm ideas for including the person with a disability in the community and setting up a social support network.

**7. Help the person to develop a positive identity.** A person with challenging behavior commonly gets identified as a "problem," which carries a negative message for the person and those around him or her. Build a positive identity by helping the person find a way to make a contribution and better support those in his or her life. Make sure that the person's strengths and capabilities don't get overlooked when reducing or eliminating challenging behavior.

**8. Instead of ultimatums, give choices.** If the person uses challenging behavior to express needs, give the person choices and allow the person to make choices throughout the day. Choice does not mean free rein. Set limits with the input of the person with a disability. Every relationship has limits.

**9. Help the person to have more fun.** Fun is a powerful cure for problem behaviors. Look for things the person enjoys doing. Add to that list. Make fun a daily goal.

**10. Establish a good working relationship with the person's primary health care physician.** Many people exhibiting challenging behavior don't feel well. Being healthy is more than being free of disease or illness. It also means a balanced diet, good sleep habits, and other good health factors. Sudden behavior problems might be related to not feeling well. By knowing the person's general health, talking to those who know him or her, and having good contact with a primary health care physician, you can more easily figure out the reason for the challenging behavior.

Information for this fact sheet is from "10 Things You Can Do to Support a Person With Difficult Behaviors," David Pitonyak, *The Community Journal,* Summer 1997 published by The Commonwealth Coalition for Community, P. O. Box 10704, Blacksburg, VA 24060. The Beach Center offers an expanded version of this fact sheet, see p. 19.

# Beach Center Updates

**WWW page.** The Beach Center will debut its positive behavioral support page next month. The site will feature a subject overview, fact sheets, articles, model statute, research reports, resources, success stories, and an on-line instruction class. Find the web page at http:\\www.lsi.ukans.edu\beach\pbs.htm

**New journal.** Pro-Ed will publish a new journal dedicated to positive behavioral support, school and community-based interventions, program descriptions, and family support articles. The first issue is scheduled for January of 1999.

**Keynote presentation.** Rud Turnbull and Ann Turnbull gave a keynote presentation Oct. 26-28 at the Parent Training and Information Conference sponsored by the Office of Special Education and Rehabilitative Services in Washington, D. C. The positive behavioral support presentation emphasized the translation of research findings into best practices. From that presentation, the Beach Center is developing a trainer-of-trainer's pack for Parent Training and Information Centers. Contact the Beach Center for further information.

**Fathers' participation in child care programs.** Dr. Vicki Turbiville and other Beach researchers have completed their study of 318 fathers of children attending four different types of childcare programs and of 198 providers in six states. Of fathers surveyed, 80% indicated some level of participation in their child's childcare program. They preferred activities in which their wives were involved rather than men-only activities. Being specifically invited to participate encouraged fathers to participate as did parent activities scheduled in the evenings or on weekends.

**Medical and dental grant.** Beach Center staff Amanda Reichard, Rud Turnbull, and Richard Viloria currently are conducting a survey of consumers, physicians, and dental professionals in Kansas to ultimately increase the capacities of health care professionals to meet the health care needs of individuals with developmental disabilities and their families. A related project with the Child Development Unit at The University of Kansas Medical Center will recommend solutions to eliminate health care barriers for individuals with developmental disabilities.

**Guardianship.** As part of the Beach Center's ongoing state policy review, Amy Buchele-Ash and Rud Turnbull are revising guardianship, commitment, and abuse and neglect civil statutes at the request of Kansas officials. The closing of state institutions has prompted this revision.

*Families and Disability (ISSN: 1044-8217) is published three times a year by the Beach Center on Families and Disability at The University of Kansas. Copyright. 1998. There is no subscription charge. Funding for Families and Disability is provided by the National Institute on Disability and Rehabilitation Research (NIDRR), U. S. Department of Education, Office of Special Education and Rehabilitative Services, Grant #H133B3007-95. Opinions expressed in Families and Disability do not necessarily represent the views of NIDRR or The University of Kansas. Editor: Cindy Higgins.*

## For a free subscription to Families and Disability Newsletter, fill out this order form

Name_____
Organization_____
Address_____
City, State, Zip_____
Phone_____
Email_____

*and return to The Beach Center on Families and Disability, 3111 Haworth, The University of Kansas, Lawrence, KS 66045-7516 (785-864-7600 V, TDD; 785-864-7605 (FAX) or Beach@dole.lsi.ukans.edu*

# Check It Out

❑**Encourage Desirable Behavior in Children With Developmental Disabilities (English).** Fact sheet. 1994. $.50. (1S)

❑**Encourage Desirable Behavior in Children With Developmental Disabilities (Spanish).** $.50. (S1A)

❑**Reduce Challenging Behavior in Children With Developmental Disabilities (English).** Fact sheet. 1994. $.50. (2S)

❑**Reduce Challenging Behavior in Children With Developmental Disabilities (Spanish).** $.50. (S2A)

❑**Find a Qualified Behavior Specialist.** Fact sheet. 1997. $.50. (12S)

❑**Discipline and Punishment.** Fact sheet. 1997. $.50. (15S)

❑**Ten Ways to Support a Person With Challenging Behavior.** Fact sheet. 1998. $.50. (18S)

❑**What You Should Know About Person-Centered Planning (English).** Fact sheet. 1996. $.50. (6G)

❑**What You Should Know About Person-Centered Planning (Spanish).** Fact sheet. 1996. $.50. (S6G)

❑ **Functional Assessment Questionnaire.** 1997. $3.00. (17S)

❑**Samantha.** Video of successful positive behavioral support plan for 9-year-old girl with autism. See 6S and 14S. $30.00. (10S)

❑**Why Does Samantha Act Like That? A Positive Behavioral Support Story of One Family's Success.** Tells family story and includes plan charts, pictorial history. 1994. $5.25. (6S)

❑**What Research Says: Understanding Challenging Behavior and Teaching New Skills.** Presents findings in easy-to-read booklet. 1995. $2.00. (8S)

❑**Positive Behavioral Support as a Means to Enhance Successful Inclusion for Persons With Challenging Behavior.** Describes components of positive behavioral support. 1994. $4.50. (4S)

❑**Research Brief: Challenging Behavior and Inclusion.** Summarizes Beach research on families experiencing challenging behavior. 1995. $.50. (9S)

❑**Research Brief: Stakeholder Views on Challenging Behavior of Persons With Mental Retardation or Autism.** Summarizes Beach research. 1997. $.50. (16S)

❑**Family Perspectives on Inclusive Lifestyle Issues for Individuals With Problem Behavior.** Journal article reprint (*Exceptional Children,* 1997). $2.50. (11S)

❑**Positive Behavioral Support Model Statute.** $4.00. (19S)

❑**Managing Crisis in Your Life: Designing Your Volcano.** A kit designed to help children with emotional behaviors overcome behavioral problems. $12.99. Order directly from *Keys for Networking* (785-233-8732).

## To Order

Please indicate the number of copies you want beside each listing, add $ amounts, then write price total in space below.

Shipping and handling are at no additional cost.

Prepay all orders.

*Send products to:*
Name/Organization_____
_____
_____
_____

Address_____
_____
_____

City, State, Zip_____
_____

*Bill to (if different than shipping address):*
Name/Organization_____
_____
_____
_____

Address_____
_____
_____

City, State, Zip_____
_____

Mail (total)$_____
in U. S. dollars to:

The Beach Center on Families and Disability, The University of Kansas, 3111 Haworth, Lawrence, KS. 66045, 785-864-7600 (phone), 785-864-7605 (FAX)

_____**Yes! I would like to receive the Beach Center newsletter at no charge.**

# Newsletter User Survey

*Families and Disbilities Newsletter* is one medium that the Beach Center uses to publish research results produced by Beach Center researchers. All articles are produced at the Beach Center and relate to each newsletter theme. Please fill out this survey. Your response will help us improve our information delivery. *Please mail to: Stephen Pollard, Beach Center on Families and Disability, 3111 Haworth, Univ. of Kansas, Lawrence, KS 66045.*

1. What is your general response to *Families and Disabilities Newsletter?*
____ Very positive
____ Fairly positive
____ Neutral
____ Somewhat negative
____ Strongly negative

2. After you finish reading this newsletter, do you
____ Throw it away
____ Save it for reference
____ Pass it on to others to read
____ Use it in training or other purposes
____ Republish the information

3. How much of *Families and Disability Newsletter* do you usually read?
____ All or most
____ Headlines and some articles
____ Headlines only
____ Don't read it all

4. How has *Families and Disability Newsletter* been useful to you?
____ Introduces me to new topics and issues
____ Keeps me up-to-date
____ Provides good background material
____ Other_____

5. How can future issues be improved?
____ Increased publication frequency
____ Longer articles
____ Shorter articles
____ More resources
____ More family stories
____ Other_____

6. Do you have access to the World Wide Web?
____Yes
____ No

7. If yes, have you seen the Beach Center homepage (http://www.lsi.ukans.edu/beach/b) and read our newsletter there?
____Yes
____No

8. Please write any additional information here regarding your opinions about *Families and Disability Newsletter.*

The University of Kansas
Beach Center on Families and Disability
3111 Haworth Hall
Lawrence, KS 66045-7516

EC 306197


**U.S. DEPARTMENT OF EDUCATION**
*Office of Educational Research and Improvement (OERI)*
*Educational Resources Information Center (ERIC)*

# NOTICE

## REPRODUCTION BASIS

☐ This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

☑ This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").