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Family Perspectives on Problem Behavior

Ann P. Turnbull and Mike Ruef

Abstract: Data from interviews with 17 families who have a member with mental retardation and problem behavior were reported. The interview was focused on the families' definition of problem behavior, current challenges they face, and successful approaches for helping individuals with problem behavior and their families as well as suggestions from families about what kinds of information they believe would help them in addressing challenges. Key recommendations focus on the implications of this information for research, demonstration, and training activities.

The mental retardation literature concerning problem behavior is primarily limited to documentation of families' or service providers' priorities and perspectives (Meyer & Evans, 1993; Turnbull & Turnbull, 1993). One exception is an article by Dunlap, Robbins, and Darrow (1994) that provides a survey of parents' priorities. Parents of children with autism and related disabilities identified teachers, other family members, and published materials as the most helpful resources currently available and contingency management as the most effective management approach in addressing problem behavior.

Research is primarily available only to other researchers, and, typically, families and service providers have limited access to state-of-the-art information (Fuchs & Fuchs, 1990; Kaufman, Schiller, Birman, & Coutinho, 1993; Meyer & Evans, 1993). Such a discrepancy between empirical knowledge and user need is not confined to the topic of problem behavior. A research-practice dichotomy is a concern consistently identified throughout the social science literature (Hoshmand & Polkinghorne, 1992; Huberman, 1990; Kaestle, 1993; Lather, 1986; Zarb, 1992).

The present study was designed to mitigate this dichotomy by focusing on parents' perspectives toward problem behavior of individuals with mental retardation. In this study, which is a component of a larger study, we addressed the following research questions: (a) What are family perspectives about the current challenges and successful approaches for *individuals* with mental retardation who experience problem behavior? (b) What are family perspectives about the current challenges and successful approaches for *families* of individuals who experience problem behavior? (c) What type of information do families want (e.g., sources, topics, formats) that would make a significant and sustainable difference in reducing or eliminating

problem behavior? In addition to addressing these questions in this article, we have discussed an unanticipated category of information – family definition of problem behavior – that emerged in the data analysis.

Method

Interviews were conducted via telephone because (a) it is an inductive approach that allowed us to develop rather than test hypotheses by enabling participants to identify and describe issues important to them, and (b) we were able to choose participants from diverse geographical locations to be part of the sample without incurring significant travel costs.

Participants

Because the term *problem behavior* is open to many interpretations, we used the following criteria to identify participants whose problem behaviors were related to our area of interest: (a) aggression toward others, property destruction, self-injurious behavior (SIB), or pica exhibited at least one time during the previous 4 years; (b) five or more episodes of one of these four types of problem behavior displayed within a 2-week period within the last 4 years; and (c) mental retardation. Based on these criteria, we developed a screening instrument to use in the initial contact with families.

We sought nominations of families from approximately 43 sources, such as parent organizations, parent training and information centers, family advocates, and programs that provide positive behavioral programming services. When we contacted representatives of these organizations, we reviewed with them the screening criteria related to the problem behavior definition and encouraged them to nominate families representing a broad spectrum of socioeconomic circumstances, problem behavior

severity, age of target individual, ideological orientation, current service provision, and extent of family challenge. They nominated 21 families. After we administered the screening instrument, we found that 4 of these families did not meet criteria.

We interviewed respondents from 17 families. Table 1 includes family demographic and individual placement information. For 2 of the families, we spoke with more than one family member: In one situation, we interviewed the mother, father, and brother, and in the other, in addition to the mother we interviewed the target individual's roommate/close friend, who was regarded as an extended family member. The mother was the respondent in 15 of the interviews and the father in 3. (Among the reasons for the high number of mothers rather than fathers as respondents were: [a] 5 mothers were single parents, [b] agency staff most frequently recommended mothers as respondents, and [c] the initial calls were made during standard working hours.) In 3 families, all members had less than a high school diploma; 4 families had one or more members who had completed graduate school. The families were from a broad spectrum of community types: Approximately half were from suburban communities, and the other half were equally divided between large cities and small towns/rural areas.

Data Collection

The interviews, which were conducted over a 5-month period, were completed over the telephone by one of the three interviewers. Two of the interviewers, who conducted approximately half of the interviews, used a speaker phone. The interviews ranged from approximately 30 minutes to 120 minutes, with an average of approximately 70 minutes per interview. Our goal was to have families discuss their priority interests. Interviews conformed to S. J. Taylor and Bogdan's *(1984)* description as: "a conversation between equals, rather than a formal question and-answer exchange" (p. 77).

After nominations were received and consent obtained from families, an interviewer called the family, explained the purpose of the study, and asked whether one of the parents would be willing to complete a screening instrument to determine whether their son or daughter met the study's criteria for problem behavior. A mutually convenient time was scheduled for the telephone interview with each family respondent who met the screening criteria, and he or she was called at this later time.

Table 1

Family Demographic and Individual Placement Information

Family No.	Respondent	Racial/ethnic Status	Marital Status[a]	Age of Child	School Placement[b]	Employment[c]	Home Placement
1	Mother	EA	M	2	SE, VE	N/A	Family
2	Mother	EA	M	8	C	N/A	Family
3	Father	EA	M	10	C	N/A	Family
4	Mother	EA	M	20	VE	N/A	Family
5	Mother	EA	M	9	C	N/A	Family
6	Mother	EA	D	36	N/A[d]	NE	Other[e]
	Roomate	EA	S				
7	Father	EA	M	22	N/A	NE	Family
	Mother	EA	M				
	Brother	EA	S				
8	Mother	Latino	D	7	SE	N/A	Family
9	Mother	Latino	M	9	SE	N/A	Family
10	Mother	EA	M	8	SE	N/A	Family
11	Mother	EA	M	4	RE	N/A	Family
12	Mother	EA	D	18	SE	N/A	Other
13	Father	EA	M	7	RE	N/A	Family
14	Mother	Latino	D	10	SE	N/A	Family
15	Mother	EA	W	28	N/A	NE	Other
16	Mother	EA	M	25	N/A	VE	Other
17	Mother	Latino	M	15	SE	N/A	Family

[a]M=married, D=divorced, S=single, W=widowed. [b]SE=special education, VE=vocational education, C=combined special and regular education, RE=regular education. [c]NE=not employed, VE=volunteer employment. [d]Not applicable. [e]Roomate, group home.

In the initial interviews the three research questions were used as a general guide, but respondents were encouraged to address issues most important to them. As interviews were completed, the research team continually met to discuss emerging themes and categories, which were later used, when appropriate, as general probes. All interviews were tape recorded and transcribed.

Data Analysis

The constant comparative method of analysis was used to analyze the data (Glaser & Stauss, 1967). This method was carried out by unitizing, individually categorizing, and team categorizing the data (Skrtic, 1985). The research team unitized by reading each transcript and identifying informational units considered relevant to the broad research questions. The units were then entered on index cards with the full language as it appeared on the transcript. Each card was coded by respondent and transcript page number.

The individual categorization process involved sorting unit cards into groupings of similar content while devising categorization rules as a research team. The research team defined categories in an analytic – inductive fashion and identified new categories when informational units did not fit previously defined categories. After two of the interviews were completed, individual categorizing began and continued throughout the data-collection process.

Individual categorizing and team categorizing occurred simultaneously. Individual team members unitized and categorized data after each interview. After segments of two to three interviews, team meetings were held to discuss the previously agreed-upon categories and any newly emerging categories suggested by the informational units. In this fashion, new categories were added to the evolving interview guide as general probes that could be used during the upcoming interviews. Frequency and duration of topics raised by the families were viewed as indicators of topic salience.

To establish credibility of the categorization and interpretation of data (Lincoln & Guba, 1985), we sent a manuscript draft to all families who participated in the interview (member check) and to an advisory committee of the sponsoring research organization (stakeholder review) to elicit their comments on the extent to which the report accurately reflected their perspectives and any suggestions they had for improvement. As part of the member check, we sent all 17 families a feedback questionnaire, which contained 10 specific questions on the degree to which the results and discussion were consistent with their perspectives and an open ended question encouraging any reactions and suggestions. No families expressed any significant concerns. The only corrections made related to spelling and small edits of some quotes. Several families indicated strong endorsement of the information contained in the paper. They particularly noted how refreshing it was to read a paper that genuinely reflected not only their "family reality" but also the reality of other families they knew. The stakeholder review involved sending the paper to 8 family leaders who provided consulting advice to the researchers. These leaders represented different regions of the country and three racial/ethnic groups: Latino, African American, and Euro American. None of the stakeholders expressed specific concerns.

Findings

Findings focus on how families described (a) their definition of problem behavior, (b) current challenges associated with and successful approaches for dealing with *individuals* who have problem behavior, (c) current challenges and successful approaches related to the impact of the problem behavior on *families,* and (d) their current access to and preferences for relevant information in minimizing problem behaviors and enhancing successful approaches. In much of the discussion of findings, we have used the term *families* in light of the fact that the respondents included 15 mothers, 3 fathers, 1 sibling, and 1 friend/roommate (who was regarded as an extended family member). We do caution that the term *family* may be misleading, given that the significant portion of comments came from mothers, who also provided the significant amount of caregiving within these families. Although the study was not designed to illuminate specific gender issues, we do want to acknowledge the important role of mothers in providing these data.

Family Definition of Problem Behavior

In the initial screening interview, 14 of the 17 families indicated that their son or daughter had mental retardation and/or engaged in at least one of the four categories of problem behavior: aggression toward others, property destruction, SIB, or pica. For 14 families, the dangerous behavior had occurred (a) at least one time during the previous 4 years, and (b) there had been at least one 2-week period within the previous 4 years in which there were five or more episodes. (The 3 families who did

not report this extent of problem behavior provided comprehensive positive behavioral support in all of their child's activities. Two of the families were unsure as to whether their family member had mental retardation: One of these families had recently had success with facilitated communication, and 2 of the target children were

preschoolers.) With regard to level of mental retardation, respondents described approximately one third of the individuals as having either mild, moderate, or severe mental retardation, respectively. Almost all of the parents described their son or daughter as having autism, even though autism was not one of the screening criteria.

Table 2
Families' Definition of Problem Behavior

Dimension	Dangerous Behavior	Difficult Behavior
Observable behaviors	"He broke the windshield out of the car recently – this is one of his high skill areas."	"When I am around him it is constant noise. He talks or squawks. By afternoon I am frazzled."
Families' perceptions	Fear/Worry: "Our greatest fear is that she will do something so awful that she will be locked up. We live in fear of that."	Concern/Embarrassment/Annoyance: "I am always thinking about his behavior. It is always in the back of my mind anytime we bring him anywhere."
Others' perceptions	Fear/Worry: Teacher fears that child will tear earring out of a classmate's ear.	Concern/Embarrassment/Annoyance: "One time I took George to the supermarket, and he kind of jumped up and down and rocked and hummed. He was laughing a lot, and a woman gave me a look. She wouldn't dare say anything, but she gave me a look almost to say, "Why would you bring a boy like that in here?" She didn't have to say anything. Her look told it all."

The families' descriptions of problem behavior, an unanticipated category that emerged in data analysis, were substantially more multidimensional than was the problem behavior description used for screening in this and many research studies. Families discussed two major domains of problem behavior: (a) dangerous behavior and (b) difficult behavior. For both dangerous and difficult behavior, three dimensions appear important to understand when considering families' perspectives of problem behavior: (a) observable behaviors, (b) families' perceptions of behaviors, and (c) others' perceptions of behaviors. Table 2 depicts this six-dimension conceptualization.

Dangerous behavior. Although 14 families indicated that their son or daughter had engaged in dangerous behavior (e.g., aggression toward others, property destruction, SIB, or pica), they did not spend substantial time describing these incidences. Families tended to report observable behavior (first dimension) in a rather matter-of-fact manner without a lot of elaboration and description: "He punches his face a lot on the jaw line-his cheek bone, his mouth, occasionally

his forehead. . . . He will eventually bleed from his mouth."

For the second dimension, family perception (i.e., fear, worry about the behaviors), the families' primary perception was fear. Even though the dangerous behavior was *episodic,* some families reported an *incessant* fear that the behavior was going to happen. For example, one parent commented, "Our greatest fear is that she will do something so awful that she will be locked up. We live in fear of that." Thus, even though dangerous behavior was episodic, this family and a number of others worried *every day, throughout the day,* that the behavior would occur. The actual behavioral occurrence did not correlate with the mental occurrence or dread of it.

The third dimension relating to dangerous behavior is the perception (i.e., fear, worry) of others' reactions. One father reported his intense commitment to school inclusion but noted his daughter's general classroom teacher's concerns and hesitations. He said that the teacher anticipated worst-case scenarios, particularly a pervasive fear that his daughter would tear the earring out of a classmate's ear. Although his daughter had *never* engaged in this specific

behavior at all, the teacher's fear, in a sense, prevented her from implementing inclusion successfully. His daughter was *consistently* regarded as though she had exhibited this behavior, even though it had never actually occurred. Others' fears were reported by many parents to escalate their own fears so that they tended to live in a "crisis mode," even though their son or daughter might actually have relatively infrequent dangerous behavior.

Difficult behavior. Difficult behavior was described as creating constant demands for supervision, making the child stand out from others, and provoking others' embarrassment *or* annoyance. (Difficult behavior was not included in the screening criteria.) The same three definitional aspects we found for dangerous behavior were also found for difficult behavior. The first is the observable behaviors themselves: "The most difficult behaviors are those that make him bizarre, such as flapping, moaning, and screeching."

What was more significant in the family descriptions of this category were not the observable behaviors themselves, but the constant attention by parents because of the behaviors. This incessant demand for attention was by far the most frequent theme that parents addressed as they described problem behavior: "Problem behavior is her incessant demand. What are we going to do next? Then what? ... There is no down time for those involved with her." The saliency of the incessant demand for attention and resulting affective responses because of these difficult behaviors was striking.

The second dimension focuses on the families' perceptions (i.e., concern, embarrassment, annoyance) about the difficult behavior. In addition to the incessancy of some of these behaviors, there also appears to be a continual worry, especially in public, about the behavior's impact on the family and others.

If he has to pass gas, he'll just do it. He doesn't conceive or understand embarrassment. If he has to use the bathroom, he'll say, 'Have to go to the bathroom.' He is not worried about embarrassment, but I am.

Even for behaviors that do not occur incessantly (e.g., passing gas), families reported an incessant *worry* that the behavior was going to happen. Thus, the behavior may have been episodic, but the worry was constant. Families often pointed out that this kind of embarrassment is particularly hard on siblings.

The third dimension is others' perception (i.e., embarrassment, concern, annoyance) that often only heightens the families' concerns, embarrassment, annoyance, and/or feeling of being an imposition on others. Almost all families reported worry and concern about others' reactions, which often resulted in a community outing being stressful, exhausting, depressing, or disappointing rather than relaxing, enjoyable, and/or rejuvenating.

Current Challenges in and Successful Approaches for Dealing With Individuals Who Exhibit Problem Behaviors

Respondents identified six major challenges in providing support for individuals with problem behavior: (a) assessing problem behaviors, (b) incorporating structure in home routines, (c) enhancing communication, (d) expanding relationships, (e) increasing choice-making, and (f) de-escalating stress. In some cases, these families have found successful approaches to minimizing the challenges.

Assessing problem behaviors. Most respondents expressed a great deal of frustration about the problem behavior. Equally frustrating was the fact that neither they nor the service providers they worked with had an adequate understanding of the nature of the problem behavior and/or the specific antecedents that triggered it. The roommate of one of the adults advised:

Look for what is behind behavior; people need to take time and effort necessary to understand that there is a REASON for the behavior. It doesn't just come out of the blue.

Parents stressed that professionals need to refrain from blaming the individual and/or family members for the problem behavior and, rather, should systematically identify the environmental factors that escalate the behavior.

Structuring home routines. Many families commented on their son or daughter's lack of ability to play or engage in leisure independently, handle changes in routine, cope with frustration of misplacing a valued object, or handle what is going to happen next. Two subthemes emerged in this category: (a) need for a structured and predictable daily schedule and (b) need for more support in managing daily routines. In terms of the need for a structured and predictable schedule, one parent charac-

terized the problem as follows:

If he doesn't know what we are going to do, then he gets real anxious and what he would do in this situation is to start to unload the refrigerator about 90 miles per hour and continually. We would just get him out of it, and he is back in it again. He begs to eat, even though you know he's full. Or he begs to get a drink, even though he just had a drink. It just never ends.

Several families reported frustration and disappointment about their child's inability to be engaged with toys and hobbies.

The second subtheme relates to family routines and the stress that the problem behavior injects into family routines (e.g., meals, sleeping, and weekends) and the need for more support in managing these routines. A couple of the families described particular problems with mealtimes, including restrictive food preferences and disruptive mealtime behavior. Several families also mentioned that their son or daughter only sleeps 2 or 3 hours a night.

Parents frequently described the weekends as being particularly problematic. At a time when many families whose sons or daughters do not exhibit problem behaviors have at least some opportunity to rest and relax, these families indicated that the lack of weekend structure (e.g., school not being in session, other family members wanting downtime) resulted in significant family stress. The family who indicated the most weekend success had developed many options for providing home structure, such as a picture schedule board for weekend activities and regular times for meals with a highly structured and predictable way of serving meals. (They also expressed frustration over having no down time themselves.)

Many families emphasized a need for more assistance in creating structure and organization throughout their total home environment, 7 days a week, 24 hours a day. They lamented that typically service providers do not see this as part of "their job."

Enhancing communication. Quite a few respondents indicated that their son or daughter's lack of ability to communicate effectively was the cause of problem behavior: "The only way that she can express herself is beating her chest with both hands." Families also expressed frustration in not being able to communicate effectively with their son or daughter and not having augmentative communication devices. A mother lamented, "He needs a communication device. I can't pay for it. They said they would

try through Children's Resources to get one, but they haven't contacted me back." Several families described successful strategies of teaching their children to shake hands and say "hello" rather than hitting someone and to ask for a break rather than having a tantrum.

A number of parents emphasized the importance of nonverbal communication. One mother underscored the significance of others learning how to have a conversation with her son, who is nonverbal. Other families pointed out the importance of gestures in expressing positive emotion – kissing, smiling, and smelling parents' hands. Some respondents noted that bad behavior was the only strategy their son or daughter had for expressing negative emotions. Families indicated a need for more verbal and gestural communication for expressing negative emotions.

Expanding relationships. Families expressed an extraordinary void in emotionally connected, reciprocal relationships between their son or daughter and others in family, school, and community settings (Turnbull & Ruef, in press). In terms of family interactions, respondents highlighted particular problems in relationships with siblings and extended family. The majority of families expressed long-term and continuing problems related to sibling issues. Approximately half of the families commented on relationships with extended family members; a consistent theme was that the extended family members often give the impression that they think the individual's behavior problems are because of poor parental discipline. Families made a number of poignant descriptions of the child or adult with problem behavior virtually being ignored at family reunions or gatherings.

Although family relationships were troublesome, the most pervading comments on relationships mentioned the absence of friendships for the children and adults with problem behavior. Sample comments included: "George knows a lot of people, but he doesn't hang out with them." "Danny has no relationship outside his family." Not only did the families describe almost a total absence of friendships, but the disappointment and pain reflected in those descriptions is highly noteworthy.

Similarly, families reported very minimal connection to community activities. Only about one third of the families mentioned participating in clubs or recreational activities. Parents pointed out that many community settings are confusing, crowded, and unpredictable, thus presenting particular

challenges for people whose behavior tends to be more problematic under these conditions. A key catalyst for the individuals who did participate in some community activities was usually a paid companion who accompanied them in various activities. A couple of families provided their car for the paid companion to drive.

Almost all families expressed a need for more support in helping family members and significant others in all environments connect with the target individuals in a way that represents a genuine relationship. One parent pointed out the importance of other people observing the target individual engaging in close and loving relationships:

It is very powerful for others to see her with people who love her and want to be with her instead of with a paid staff person who is frustrated and doesn't want to be with her. This is a key issue.

Increasing choice-making. Several parents strongly emphasized the importance of their son or daughter making choices and enhancing his or her skills in choice-making. They seemed to agree that many of the school activities or the recreation planned by group home staff members tended to be routinized without giving their sons or daughters an opportunity to make a choice. In terms of recreation within group home settings, a couple of the parents gave examples of how everyone in the group home goes to the same movie without an individual being able to express a preference for the movie that he or she would like to see. One parent commented:

We need to teach him how to use language as a way to request or to control others. He needs a day-to-day program allowing him to make more and more independent decisions and gain more and more control over his own environment.

This mother also pointed out that significant others need more awareness and understanding of how to create opportunities for people with problem behavior to make choices, including what they perceive to be bad and good choices. She emphasized how much people with problem behavior need to face the consequences of their choices and that others need to recognize them as "self-determiners."

De-escalating stress. Families pointed out several stress management approaches (e.g., deep breathing, self-talk) to help decrease frustration rather than letting frustration build up to explosive behavior. A frequently mentioned approach was the creation of "safe places" that are familiar and secure "niches" in which people can "pull themselves together." As one respondent noted: "Kids must have the opportunity to exclude themselves so that they and others will be safe. One incident can set everything back." Another mother commented that "people's attitudes" are one of the key characteristics of a safe place.

Current Challenges and Successful Approaches Related to the Impact of Problem Behavior on Families

The data reported in this section focus on family perspectives concerning the current challenges and successful approaches related to their own sense of well-being. The two major challenges and some corresponding successful approaches related to the impact of problem behavior on family members include (a) sustaining energy levels and (b) engaging in advocacy.

Sustaining energy levels. Two subthemes emerged related to the critical importance of families' sustaining their energy level: (a) the importance of time away and (b) other strategies for renewing interest. Families reported tremendously busy schedules representing all different types and levels of family responsibilities. One mother described her situation as follows:

My husband is a full-time Ph.D. student and is gone from 8:15 a.m. until 10:30 p.m., so I have to hold down the fort at home. We have two other children and one on the way. I am under a lot of stress.

Another mother whose only financial support was welfare described going to school all day, getting home at 5:30, making dinner, doing housework, doing homework, and trying to manage her child's behavior.

Mothers, in particular, consistently emphasized the need for breaks and a chance to relax; however, they reported the chronicity of their being "on duty." They characterized "home" not as a place of security, privacy, and time off from competing responsibilities of daily living but rather as a place for maintaining sometimes 24 hour duty.

The most frequently mentioned issue was the parents' need to have time off from dealing with the problem behavior issues. Parental

preferences varied greatly for how to spend time off: physical fitness workouts, sports activities, going out as a couple, and involvement with parent organizations. Mental time off was described as being at least as important as physical time off. Most mothers pointed out that in the rare occurrences of having physical time off, they typically experience feelings of guilt and worry (see Table 2). Thus, one cannot assume that physical time off is commensurate with mental time off.

Several families expressed how helpful it would be if there was a place where their son or daughter could occasionally spend the night. One family who had an 11-year-old son indicated that they had spent one night away from him in his entire life. They suggested that it would be ideal if there were a place he could go every 3 months for a couple of nights where he would have a good time and have a sense of security (i.e., they would not worry about him), so that they could have a chance to renew their energy through physical and mental time away. One family indicated that they had tried an overnight arrangement, but their son's way of showing that he missed being at home was not to sleep or eat breakfast. Whether the child spends a night away or spends the day in a supportive and supervised place, families commented that it would be very helpful to them to have time at home alone. Summer camps were also mentioned as a preferred option, but none of the families reported having had success with camping experiences.

A number of families mentioned vacations as an option for time away from daily responsibilities but also the double-bind that vacations present. They described the extreme difficulty of taking their child on a vacation but mentioned that they would feel guilty if they did not take their child along.

The second subtheme related to sustaining energy level focused on the expressed needs of having strategies for renewing interest such as drawing on religious faith and deriving support from other people. Some families mention drawing on their religious faith as a support: "We are Catholic, and I know we can draw on that. There are always divine interventions when I was ready to self-destruct." Although religious faith was mentioned by several families as a significant source of support and encouragement, over half of the families expressed disappointment and frustration concerning the impossibility for them of participating in their preferred religious

community as, a family unit because of the lack of adequate supports in dealing with the problem behavior (Turnbull & Ruef, in press).

In terms of deriving support from other people, the most frequently mentioned helpful strategy was drawing on other people's hopefulness, including that of professionals, who share a vision of what is possible for people with disabilities, having access to people who will say things such as "go for it!", spending time with other parents who share similar visions, and having friends who believe in the ability and future of the person with problem behavior. On this last point, a mother commented: "At a critical time, one of my good friends said, 'Don't give up, don't lose faith.' It was real energizing to know that others believed in my daughter, too."

Engaging in advocacy. All of the parents reported advocating at one time or another. At least half had invested extraordinary time and energy in advocacy-one parent had invested 35 years in unrelenting advocacy. There were a number of different catalysts for getting involved in advocacy, including the support of state-of-the-art professionals, fear of placement in a state facility, fear of what will happen after the parents die, concern that the program will always be inadequate unless the parents work to change it, and a crisis event that transformed the parents' mission to accomplish a certain goal. On this last point, a parent commented:

In my experience, it takes some crisis event in your life to get really involved. For me, it was the time-out box. It lit my fire and there is no stopping me now."

Parents alluded to feeling empowered by their advocacy efforts but also feeling drained. For example, one parent noted:

When I get frustrated ... in thinking that things are never going to change ... and wondering if it is just me ... I just back off for a while, rejuvenate, and go again.

One family reported that both the mother and father lost their jobs because of the time they were spending on advocacy every week.

The final suggestion that 2 mothers mentioned was that it would be helpful to receive monetary rewards for their advocacy efforts. Both mothers invested tremendous time in advocacy for their own child as well as for other children with similar challenges. They realized how many volunteer hours they were putting into advocacy, and they needed paid employment.

Family Perspectives on Helpful Information

Because respondents did not spontaneously mention information they would find helpful, we solicited comments. The probable reason that few parents spontaneously brought up this topic is that most of them have not gotten much helpful information from any source. The comments made addressed sources, topics, and formats.

Sources. Parent respondents named a few organizations and publications that provide information that helped them in dealing with problem behavior. No organizations were, referred to consistently. Few helpful publications were listed. One family noted the newsletter of a national parent organization. The only written information mentioned was an article in *People* magazine, newspaper articles, and a list of famous people who have been identified as having autism (which gave the responding parent hope that people with autism can successfully function in society).

Topics. Families pointed out the importance of having topical information on (a) specific issues related to problem behavior exhibited by the child or adult and (b) family support issues. In terms of information topics related to the son or daughter with problem behavior, the most frequently mentioned need was for practical information that can be applied in real situations. As one respondent noted, "Parents need strategies for applying information. We need real, concrete, follow-through ideas."

Several parents also emphasized how important it is for parents to have hope that things will be better, indicating that one of the best ways to help create hope is to share stories of parents who have been successful in similar situations. Another important need is for information on how families can maintain equilibrium, and even composure, when behavioral incidents occur, especially when they happen in public.

Family members themselves also have strong needs for information related to sustaining energy levels and engaging in advocacy. Related to issues of sustaining energy levels, families reported very little access to information on how to find successful child care; make vacations enjoyable; take care of their own physical and mental health; support their son or daughter in establishing a typical sleep cycle; and maintain their energy, optimism, and health.

Parents also strongly emphasized their need for research-based information that they can use in their advocacy efforts. They discussed the importance of having "evidence" *on* a topic such as the effectiveness of inclusion and supported employment that they can share with the administrators who control service allocations and funding streams. They also expressed an interest in tips by parents who have been able to obtain services consistent with their son's or daughter's lifestyle preferences.

Formats. Parents strongly emphasized their need for print material written in nontechnical language that provides translations and summaries of research in a short, succinct, and practical way. Several parents also noted that they were interested in videotapes that demonstrated positive behavioral support techniques. In addition to having information for themselves and for service providers, several parents strongly emphasized the importance of providing information to the public through speakers, video resources, newspapers, television talk shows, and National Public Radio. A father suggested that:

The format of research needs to focus on the media and not just journals. We need to reach the parents of regular kids and distribute research to the general public.

He proposed that National Public Radio might provide a "monthly program that focuses on community integration, instead of emphasizing pathos."

In terms of who should take responsibility, one mother commented:

Parents are overloaded with responsibilities. I don't even think educating the community will happen if it is left up to the parents. It is possible that I might be able to get it done here on my own. It would make more sense for schools to address these problems as a transition issue.... It's a job in and of itself.... We need to have a team whose job it is to educate the local social services personnel, the local medical community, the local retailers. It's too big of a job for most lay people or families.

Discussion

Limitations of the Study

First, our intent in this study was to have purposive sampling rather than random, representative sampling. Although we actively sought nominations of families from 43 sources, the racial-ethnic diversity of our sample was constrained by the fact that the majority of

organizations primarily serve Euro American families. In the sample, 13 families were Euro American, and 4 were Latino. Given that the meaning and impact of problem behavior and interventions considered to be appropriate can be culturally rooted (Kalyanpur & Rao, 1991), the restricted racial-ethnic diversity is a limitation of the study.

We want to underscore the importance of refraining from generalizing from these families to all families who have members with mental retardation and problem behavior. Given that problem behavior can be defined in a variety of ways, including violence and delinquency, it is essential to place the findings and this discussion within the context of the problem behavior definition used for this study. Many of the parents used the category of autism to refer to their son or daughter's condition.

We were surprised that the representatives of the 43 sources we contacted to request nominations of families had such a difficult time in coming up with any nominations at all. This difficulty makes us wonder about the extent to which many families are substantially more isolated than are those who were part of this interview process.

The second limitation was our sole reliance on a one-time telephone interview. Had we conducted participant observations or repeated interviews (e.g., telephone or face-to-face), different issues may have emerged, although the issues may not have necessarily been inconsistent with the findings from the one-time telephone interviews.

Given the exploratory nature of the present study, we have raised issues in the following section that warrant further investigation, but we have been careful not to draw definitive conclusions.

Definition of Problem Behavior

An unanticipated finding of this study was families' multidimensional conceptualization of problem behavior, as depicted in Table 2. This conceptualization was comprised of two domains (e.g., dangerous behavior and difficult behavior) and three dimensions within each emerged (e.g., observable behavior, families' perception, and others' perception). Although we had anticipated that dangerous behavior would be of greatest concern to families, they much more strongly emphasized difficult behavior. Given our approach of defining saliency of topics by the frequency with which families discussed them, as well as by the affective intensity associated

with the discussion, clearly the constancy of demand by the family member with difficult behavior was the families' priority concern.

What most interested us, however, was that constancy must be understood by the synergistic combination of the actual observable behaviors intensified by the families' and others' perceptions. The mental fear and worry about the behavior appeared to substantially escalate the constancy of demand. Thus, the interaction of the observable behavior with concern, embarrassment, and annoyance creates eternal vigilance, as reflected in Table 2.

Another consideration is that many families are "on duty" 24-hours a day in supervising, intervening, and attempting to prevent problem behavior. Thus, the rate of observable dangerous and difficult behavior with this constancy of support cannot be equated with what the rate would be if the parents withdrew such intense support. Incessantly being "on duty" in perceiving responsibility for their son or daughter's behavior and being the "socialization agent" to ensure that others are not annoyed, uncomfortable, or judgmental extracts a significant physical and emotional toll on parents (particularly on mothers because they provide more child care) and siblings.

Similarly, the fear and worry about dangerous behavior can significantly influence how others regard the individual with dangerous behavior. An intriguing example is the child who had never torn an earring out of anyone's ear, whose father reported that the general education teacher constantly and continually worried about her doing this. Thus, the teacher's fear or worry about a perceived worst-case-scenario behavior rather than observable behavior influenced how she made decisions about appropriate classroom placement, supports, and services. Although we did not interview the teacher, she may have heard of an instance where a student with problem behavior did tear out an earring. Thus, she may have generalized that behavioral expectation to the student who was in her classroom. Alternatively, the teacher may have reported an entirely different perspective than was ascribed to him or her.

We believe that it is critical to gain a more cogent and comprehensive understanding of families', service providers', and friends' perceptions about dangerous and difficult behavior. What are the catalysts for developing these perceptions? What is the developmental sequence of the perceptions, and how do they contribute to the opportunities that students with

problem behavior have for inclusive family, school, and community experiences? In terms of restricted opportunities, one parent discussed taking her daughter to the beach when no one else was there so that there would be no infringement on others' comfort level or driving through McDonald's and eating in the car to avoid the potential for dangerous or difficult behavior to occur inside and other customers' reactions. What is the impact of these perceptions on the families' and others' stress levels, and what types of supports and services are most effective in relieving the mental anguish associated with these perceptions? More inquiry is needed on the frequency with which families' and others' perceptions lead to isolation and segregation.

Although it is typical in positive behavioral support research to deal only with observable and measurable behavior (as incorporated in the screening instrument used to identify participants), the data from this study suggest that families' and others' perceptions warrant systematic inquiry and responsive supports. There is a rather broad empirical literature related to promising approaches in learning to overcome negative perceptions through methods such as strengthening cognitive adaptation coping (Behr & Murphy, 1993; S. E. Taylor, 1983, 1989) clarifying causal attributions (Hewstone, 1989), strengthening helpful social comparisons (Will, 1984), enhancing a sense of hope (Snyder, 1994), and using humor to minimize discomfort (Lefcourt & Davidson-Katz, 1991; Lefcourt & Martin, 1986). Social psychology theory and research related to altering perceptions has been applied to specific issues within the disability field (Blue-Banning, Santelli, Guy, & Wallace, 1994; Turnbull et al., 1993). By drawing on this theory and empirical base, professionals can expand relevant support for parents, siblings, extended family, friends, teachers, co-workers, employers, and others in not only minimizing observable problem behavior but also minimizing negative perceptions about problem behavior.

Current Challenges and Successful Approaches for Individuals With Problem Behavior

The six categories identified by families as representing current challenges and potentially successful approaches underscore the importance of functional assessment and multicomponent support. Families clearly want to know more about the reasons for problem behavior. Although none of them used the term *functional assessment*, this concept was clearly very important from their perspective. Families expressed frequent frustration toward teachers, administrators, and adult service personnel for not taking the time to understand *why* problem behavior occurs. Many of the parents and the respondent who was a roommate expressed a need for a much stronger incorporation of understanding the function of problem behavior (Carr et al., 1994; Reichle & Wacker, 1993).

In addition to functional assessment, families emphasized the need for a multicomponent support approach that includes comprehensive emphasis on structuring home routines, enhancing communication, expanding relationships, increasing choice-making, and de-escalating stress. Their recommendations are consistent with the state-of-the-art positive behavioral support literature in which authors have suggested that multicomponent approaches should combine teaching new skills, making changes in how the environment is structured, and modifying the consequences for positive and negative behaviors (Carr & Carlson, 1993). Thus, the essence of their recommendations is that several discrete behavior management techniques will not provide a "quick fix" for the pervasive challenges associated with the dangerous and/or difficult behavior. A *custom-designed, multicomponent, comprehensive system of supports and services* is what families say they want and need (Turnbull & Turnbull, 1996).

Current Challenges and Successful Approaches for Families

Families' two priority issues-sustaining energy levels and engaging in advocacy-converge to underscore a dominant theme: Families feel an overwhelming sense of responsibility for trying to keep their son or daughter with problem behavior "afloat." In order to sustain their energy levels, they want and need a break from chronic responsibility. They resent the need to engage in extensive advocacy to hold professionals accountable for providing even mediocre services. In a nutshell, almost all of the families we interviewed have a sense of "going it alone." Families related anecdote after anecdote of the struggles that they have encountered to garner any kind of support; supports that they have gotten have typically been short-term and episodic rather than long-term and comprehensive.

Addressing the pervasiveness of needs, as described by the families, suggests a significant redesign of comprehensive and coordinated ways to deliver support at the individual family as well as the systems level. Families need a reliable alliance of dependable, trusted, and nonjudgmental helpers who provide assistance in the home and community with availability on a 24-hour basis (if the individual with problem behavior has a disrupted sleep schedule). These support people need to be competent in facilitating relationships between the individual with problem behavior and others within the family (e.g., siblings) and community (e.g., friends, clerks, Scout leaders, life guards). The key element is how to marshal the talents, energies, and resources of people across community environments to work together synergistically to provide positive behavioral support and to advance inclusive lifestyle opportunities for individuals who experience problem behavior and for their families.

Family Access to Information

Families made relatively few comments about helpful informational resources that they have used in the past. Because they have not had very many resources at all, they likely do not even expect information to be available or useful. Considering the amount of research that has been conducted on positive behavioral support and all of the books, chapters, and articles that have been written, it is perplexing and indicative of a significant systemic problem that the families who are dealing with these issues 7 days a week, 24 hours a day (one of whom has spent only one night away from their son with problem behavior in the 11 years since he was born) simply have not had access to this information.

Furthermore, in the literature in which investigators have discussed significant gaps between published research and practitioner utilization, they did not significantly address families as a stakeholder audience (Fuchs & Fuchs, 1990; Kaestle, 1993; Kaufman et al., 1993; Lather, 1986). Rather than conceptualizing the need for systemic change merely as an information transfer issue, researchers and stakeholders need a new paradigm to enable them to work together collaboratively for the benefit of individuals with problem behavior and have a much broader opportunity for relevant outcomes. There is an increasing number of articles in the social science literature in which investigators have called for a comprehensive redesign of relationships between researchers and stakeholders (Hoshmand & Polkinghorne, 1992; Lather, 1986). Lather addressed the extent to which researchers and "the researched" can collaborate in a process of inquiry characterized by negotiation, reciprocity, and empowerment:

Given the emancipatory intent of praxis-oriented research, I propose the less well-known notion of *catalytic validity* (Brown & Tandom, 1978; Reason & Rowan, 1981, p. 240). Catalytic validity represents the degree to which the research process reorients, focuses, and energizes participants toward knowing reality in order to transform it, a process Freire (1973) terms conscientization.... The argument for catalytic validity is premised not only within a recognition of the reality-altering impact of the research process, but also in the desire to consciously channel this impact so that respondents gain self-understanding and, ultimately, self -determination through research participation. (p. 272)

In summary, our vision for how research and training can best support individuals with problem behavior and their families is to develop apraxis-oriented research paradigm characterized by catalytic validity. Such a paradigm would enable individuals and their families to participate in research in a way that leads to problem behavior research that "reorients, focuses, and energizes participants [researchers and families] toward knowing reality in order to transformit" (Lather, 1986, p. 272).

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