

Perspectives of Five Stakeholder Groups:
Challenging Behavior of Individuals with Mental Retardation and/or Autism

Michael B. Ruef
Beach Center on Families and Disability
University of Kansas

Ann P. Turnbull
Beach Center on Families and Disability
University of Kansas

H. R. Turnbull
Beach Center on Families and Disability
University of Kansas

Denise Poston
Beach Center on Families and Disability
University of Kansas

Perspectives of Five Stakeholder Groups:
Challenging Behavior of Individuals with Mental Retardation and/or Autism

Abstract

Data from five focus groups, each representing a different stakeholder constituency interested in the challenging behavior of individuals with mental retardation and/or autism, were reported. Emergent themes across administrators and policy makers, families, friends, individuals with disabilities, and teachers and practitioners included current barriers faced; practical, positive solutions found; and preferences for helpful informational products concerning challenging behavior. Key recommendations focus on the implications of this information for research, training, and dissemination activities.

Individuals with challenging behavior, mental retardation, and/or autism place tremendous demands on the support capacities of families (Bouma & Schweitzer, 1990; Koegel et al., 1992; Quine, 1986; Robbins, Dunlap, & Plienis, 1991; Turnbull & Ruef, 1997), teachers (Billingsley, Bodkins, & Hendricks, 1993; Billingsley, 1993; Billingsley & Cross, 1991), and other caregivers. The inability of families, teachers, and other support persons to find solutions to the problems posed by problem behaviors in turn lessens the quality of life for all involved, but most especially for the person with the behavior. There are few documented examples of individuals with challenging behavior and mental retardation and/or autism who have significantly reduced or eliminated challenging behaviors and achieved enviable lifestyles. Those instances recorded in the literature described (a) a failure of the system to provide sufficient support and (b) extraordinary efforts by families to provide reasonable lifestyles for their sons or daughters (The Family Connection staff, DeVault, Krug, & Fake, 1996; Turnbull & Turnbull, 1996).

While individuals with challenging behavior and those who support them have been struggling on a day-to-day basis, a number of advances have taken place in the ways in which positive behavioral support interventions are being approached. Not only have professionals, advocates, individuals with disabilities, their families, and professional organizations called for the elimination of aversive procedures in behavioral interventions (Behavioral Interventions for Special Education Students, 1993; Guess, Helmstetter, Turnbull, & Knowlton, 1987; LaVigna & Donnellan, 1986; The Association for Persons with Severe Handicaps, 1981), but behavioral science now emphasizes a broadened approach to behavioral programming (Horner, Albin, & O'Neill, 1996) aimed at more than just focusing on the behavior and those events that immediately precede and follow it (Alberto & Troutman, 1990). Increasing quality of life for individuals with challenging behavior is now considered of equal importance with focusing on behavior alone (Risley, 1996; Turnbull & Turnbull, 1996).

The question remains, however: Why have these research advances not produced a sustainable quality of life for more individuals with challenging behavior? The reason may lie in the well-documented gap between research and practice. The nature of this gap (Carnine, 1997; Kaestle, 1993; Kaufmann, Schiller, Birman, & Coutinho, 1993; Kornblet et al., 1997)-as well as why it persists (Alberg, 1992; Chesler, 1991; Hoshmand & Polkinghorne, 1992; Malouf & Schiller, 1995)-has been described by numerous researchers. The gap between research and practice in providing support to individuals with challenging behavior lies in a perceptual difference between researchers and families, friends, and teachers as to what constitutes *relevant* research. Families and friends have stressed the importance of lifestyle change and quality of life, a concept defined by Schalock (in press) as reflecting "a person's desired conditions of living related to eight core dimensions of one's life: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights." Despite the rhetoric of many researchers that emphasizes lifestyle change and quality of life for individuals with challenging behavior, a comprehensive synthesis of positive behavioral support studies conducted between 1985 and 1996, conducted by Carr and his colleagues (1997), found that (a) lifestyle change was a stated intervention goal for only 10% of participants, (b) a formal intervention specifically aimed at improving lifestyle was mentioned for only 3% of the participants, and (c) success in improving lifestyle was measured for only 2.6% of the participants.

The present study was designed to help bridge the research-to-practice gap by examining the perspectives of five stakeholder groups (administrators and policy makers, families, friends, individuals with mental retardation and/or autism who display challenging behavior, and teachers/practitioners). The focus of this

article, which describes a component of a larger research project, is on the following research questions (which were asked of all five stakeholder groups):

1. What barriers have you experienced related to the behavioral challenges faced by persons with mental retardation and/or autism and those who support them?
2. What do you believe it would take to build positive, practical solutions to the complex behavioral challenges faced by persons with mental retardation and/or autism and those who support them?
3. What kinds of useful informational products do you believe would be most helpful in building positive, practical solutions to behavioral challenges?

Method

A combination of conference call groups and face-to-face focus groups was the source for the data collection. The focus group method was chosen because it (a) enables participants to identify and describe issues important to them and (b) creates a secure and nonthreatening environment conducive to meaningful interaction, which is especially important for groups who historically have had a limited amount of power and influence (e.g., individuals with challenging behavior and cognitive challenges, their families, and friends; Brotherson, 1994; Morgan & Krueger, 1993; Silverman, 1992; Stewart & Shamdasani, 1990).

PARTICIPANTS

The 59 focus-group participants in this study were selected using purposive sampling following procedures outlined by Lincoln and Guba (1985) and Patton (1990). For this study, the groups were structured so as to represent the viewpoints of five diverse constituencies. Depending on the stakeholder group, participant makeup was diverse with respect to some or all of the following: (a) specific stakeholder group characteristics, (b) gender, (c) age, (d) geographic location, and (e) links to disability. In addition, participants were screened by two sets of criteria: (a) general and (b) group-specific (see Table 1).

The 12 *administrators and policy makers* came from geographically diverse areas (eight states and Washington, DC), and were leaders in the area of disability. Four each were chosen from national, state, and local organizations. The 13 *family members* chosen represented geographically diverse areas (urban or rural areas in eight states) and included individuals defined to be “family”; members (see Table 1 for the definition of family) who had experience in supporting persons with behavioral challenges. Of the 10 female family members, nine were biological mothers and one was an adoptive mother. Of the three male family members, one was a biological father, one was an adoptive father, and one was considered a father by both mother and child. In two cases, both parents participated in the focus group. One family member was African American and one was a native Spanish speaker. These family members’ children with mental retardation and/or autism who displayed challenging behavior ranged in age from 5 years to 33 years. Of the 11 children, 8 were boys and 3 were girls. Eight had primary diagnoses of autism and three had diagnoses of mental retardation.

The 12 *friends* chosen represented geographically diverse areas (urban or rural areas in six states) and ranged in age from 13 years to 45 years. Ten friends were female and two were male. Eleven friendships developed through paid caregiver roles. One friendship developed at a school where students with disabilities were fully included in general education classrooms.

The nine *individuals with disabilities and challenging behavior and/or autism* chosen represented geographically diverse areas (urban or rural areas of five states). Four of the individuals were diagnosed with autism. Two of these four had difficulties communicating verbally, but none had a clear diagnosis of mental retardation. The remaining five participants were diagnosed as having mental retardation. Six of the nine individuals were men and three were women; the age range was from 24 years to 45 years. One was African American and eight were Caucasian.

The 13 *teachers and practitioners* chosen represented geographically diverse areas (urban or rural areas in nine states). Four were general educators, seven were special educators, and two were speech-language pathologists. The general education teachers had an average of 15 years experience in teaching students with disabilities and challenging behaviors (range = 3 to 25 years). Of the four general educators, one taught at the high school level, one at the middle school level, and two at the elementary level. The special education teachers had an average of 12 years experience in teaching students with disabilities and challenging behavior (range = 5 to 27 years). One worked with preschool students, two worked with elementary-age students, and four worked with middle, high school, and transition-age (ages 18-21) students. One special educator worked in a self-contained classroom for students with behavior disorders, two worked in inclusive settings (one preschool, one high school), and four worked in special education resource rooms. The two speech-language pathologists had 6 and 18 years experience supporting students with challenging behavior, represented suburban and urban geographic areas, and provided support for students ages 3 through 18 (see Note).

Ten focus groups (two for each of the five stakeholder groups) were conducted. Also, two follow-up individual interviews were conducted with the individuals with disabilities. All but the focus groups and interviews with individuals with disabilities were conducted through conference calls. The size of the focus groups ranged from three to seven persons (average = 5.5 persons). This was consistent with group sizes for telephone focus groups suggested by R. A. Krueger (personal communication, November 21, 1995). The stakeholder group of individuals with disabilities contained two subgroups—individuals with challenging behavior and mental retardation and individuals with challenging behavior and autism. One face-to-face focus group was conducted for each of these subgroups.

Participants for the eight telephone focus groups were recruited through telephone calls or personal contacts in a multistep process (Patton, 1990). Researchers sought nominations of potential participants by contacting approximately 40 people, including individual researchers, families, and teachers, as well as parent and professional groups across the country. In addition, a request for nominations was also sent to families and professionals on the mailing list of a nationwide program aimed at providing informational support to families and teachers of individuals with mental retardation and challenging behavior located at the center where this study was conducted.

If nominees indicated a willingness to participate, researchers contacted them and determined if they met the general group-specific participation requirements. Researchers selected focus-group participants from each of the five master stakeholder lists by seeking diversity in stakeholder specific characteristics,

gender, age, geographic location, and links to disability. The nature of the heterogeneity sought, however, was guided to some degree by the nature of the stakeholder group. For example, for the administrators and policy makers group, a mix of persons active at the local, state, and national levels was considered of primary importance. Participants for the individuals with disabilities subgroups were recruited in a different manner. For the focus group composed of individuals with challenging behavior and mental retardation, researchers worked with an adult agency in a university community to solicit participants. Researchers recruited members for the focus group composed of persons diagnosed with autism with the help of The National Committee on Autism. This focus group was held during the National Committee's annual conference in Arlington, Virginia, and was composed of registrants from different urban and suburban areas of the country.

DATA COLLECTION

The focus groups were conducted over a 5-month period and were completed by a team of five researchers. In order to provide consistency, the principal researcher was present as moderator or support researcher at every focus group. Moderators were varied from stakeholder group to stakeholder group, based on experience with a particular stakeholder group. At least one additional researcher was present at each focus group to operate the audiocassette recorder, keep track of time, and take accompanying notes. Each focus group lasted approximately 90 minutes. The focus-group questions grew directly out of the three overarching research questions and set the direction for the group discussion (Creswell, 1994; Knodel, 1993; Stewart & Shamdasani, 1990). In addition, a series of probes were generated to take into account the unique contributions that each stakeholder group could make (Krueger, 1993, 1994). For example, participants in the friends focus group were asked to comment on their own emotional reactions to personal experiences with challenging behavior. The focus-group probes also took into account the cognitive abilities of persons with mental retardation and/or autism using methods described by Biklen and Moseley (1988) such as avoiding open-ended questions and breaking requests for information into parts so that separate questions about each part were asked. Although the three research questions were used as a general guide, participants were encouraged to address the issues they considered to be most important to them. Our goal was for participants to discuss their priority interests regarding challenging behavior rather than to simply follow the questioning protocol in a lockstep manner (Taylor & Bogdan, 1984). As focus groups were completed, the research team continually met to discuss emerging themes, which were later used when appropriate as general probes for subsequent focus groups. All focus groups were tape-recorded and transcribed.

DATA ANALYSIS

We used a transcript-based analysis as the primary method of data analysis for this study (Krueger, 1994). This involved reviewing all field notes that included key discussion points, notable quotes, and important observations such as silent agreement or indications of group mood. It also involved reviewing summaries of debriefing sessions and transcripts from each focus group. The principal researcher and a designated second researcher first read and analyzed data separately, then met to discuss discrepancies and to reach consensus. This analysis was purposefully systematic and involved established techniques, including organization and reduction of raw data, generation of categories and codes, and interpretation of patterns and themes (Krueger, 1994; Morgan, 1993; Stewart & Shamdasani, 1990). The process of physically

organizing the data was facilitated by The Ethnograph, a computer software program capable of organizing and retrieving focus group data (Seidel, Friese, & Leonard, 1995).

Researchers ensured the soundness of the research methodology by following procedures outlined by Lincoln and Guba (1985), as well as others (Brotherson & Goldstein, 1992; Creswell, 1994; Denzin, 1978; Marshall & Rossman, 1995; Maxwell, 1996; Miles & Huberman, 1994; Patton, 1990). Principal among these procedures were peer debriefing, member checking, and a formative confirmatory analysis. Peer debriefing took place among members of the research team immediately after each focus group. During these sessions, the research team discussed key issues or themes that emerged, any significant changes in the questioning process, disagreements or varying opinions about an issue, unexpected findings, overall mood, and usefulness of the focus-group guide and questions. In addition, researchers met systematically with outside peer reviewers who read portions of the transcripts and played devil's advocates in questioning interpretations. Finally, peer review was provided by a qualitative research group that met regularly at the center where the study was conducted. The primary purposes of this group were to offer feedback on research methods proposed for individual studies and to establish center-wide research procedures considered critical in ensuring sound research methods.

Member checks were conducted at the conclusion of each focus group by summarizing the key questions and big ideas that emerged from the discussion and by asking participants if the summary was adequate and/or if any important issues had been missed. In addition, researchers sent to each participant of the telephone focus groups an executive summary of the interpretations and conclusions drawn from their respective constituency groups. Participants were asked to complete a response form to determine if the particular executive summary was "reasonable" or "unreasonable" of the constituency. Participants in the face-to-face focus groups (i.e., individuals with disabilities) were verbally asked to agree or disagree with 16 closed-ended statements representing emergent themes from the group in which they participated.

Researchers conducted a formative confirmatory analysis by constructing and organizing a labeled paper trail of relevant materials as a method for ensuring soundness. These materials included notated transcripts, a decision diary documenting when and why decisions were made, and final results. An outside expert researcher reviewed the paper trail and confirmed the overall soundness of the research process.

Findings

Due to the length and complexity of the study (there were 1,449 total coded segments of information that formed 37 distinct and meaningful units or themes), only a portion of the findings can be presented here. Therefore, this article is limited to the presentation of findings regarding themes that emerged across three or more stakeholder groups. (See Table 2 for a description of the themes and their distinguishing characteristics.) It should be noted that although some overlap exists among themes for each research question, mutual exclusivity was not a determining criterion for establishing themes. Instead, researchers sought to "identify salient, grounded categories of meaning held by participants in the setting" (Marshall & Rossman, 1995, p.114).

RESEARCH QUESTION 1-BARRIERS

Three major themes that emerged across three or more stakeholder groups regarding barriers were (a) impact of societal values, (b) inadequate school and adult service programs, and (c) additional barriers faced by support persons.

Impact of Societal Values

Four stakeholder groups addressed the subject of values. Families, friends, individuals with disabilities, and teachers described how society devalues persons with disabilities. Family, friends, and teachers explained dehumanizing values as stemming from a lack of knowledge and public awareness regarding the whole idea of disability. They all described personal experiences in trying to get people to see their family members, friends, or students as persons. One parent, for example, described the difficulty in getting people to see her son as a person:

He's had fits, you know, just temper tantrums where he just bites his hands, he stomps, he hits the wall ... and it's been very difficult to try and get people to get past all his aggression and just to get into him.

Individuals with disabilities confirmed the family, friend, and teacher statements in expressing a desire to be viewed as people and not as problems needing cures. An adult with autism commented:

I guess I wish the researchers were less negative about autism I think when it comes to things like autism, cure is irrelevant. Maybe it isn't even desirable, because if you take some of the autism stuff away, you may take the geniuses away too I'd like for people to stop demeaning those with disabilities and segregating them. I'd like places like [names private center that uses aversive methods] to be shut down immediately since I think that aversives are very punitive.

In contrast to the other four groups, administrators and policy makers had two differing stances on the subject of values. Some agreed with other stakeholder groups regarding the importance of maintaining or establishing respect for the value of each individual person and the problems that result when school administrators lack this respect. The following is a good example:

So if the teacher wants to cut the kid some slack, ignore something that's a little bit inappropriate, knowing that she [the teacher] can lead him into another kind of behavior, she'll get "chopped" for that by the principal, who's got this increasingly hard line that we're talking about: "Let's just get this kid out of the regular classroom. He doesn't belong here."

One participant also described the trap of being lulled into thinking that the answer to all educational questions lies in adding more technology or science:

People will always find new methods and finer technology behind which to retreat from treating the disadvantaged decently. And that's the way I see technology being used The answers are in values, and the fact of the matter, is we're concentrating on a group of individuals who are just horrendously devalued in our society.... Are we a community

that values children? I would say at a national level, and certainly at a state level here, I don't see that.

Other administrators and policy makers, however, spoke less of values and more of balancing equities. They spoke of solving the problems posed by challenging behavior through use of more training and more technology. Some advocated separate educational placements for students who demonstrated an inability to conform to standardized rules.

Inadequate School and Adult Service Programs

All five stakeholder groups described inadequacies in school and/or adult service programs. Administrators and policy makers described inadequacies in terms of schools and teachers hamstrung by inadequate preservice training, overly bureaucratic administrators and systems, and lack of resources. In describing the lack of preservice training, administrators and policy makers made comments such as, "I would question how many teachers have had good, solid training in working with disruptive students" and "Their weakest area is being able to manage behaviors."

Families had the most to say about the inadequacy of school and/or adult programs. Family comments addressed issues of staff, programming, and negative practices. Family comments regarding staff centered on training and attitude. Some participants were satisfied with their children's current teachers and programs, but their satisfaction seemed more a reflection of their own advocacy than of established school policies and practices. Characteristic of their comments was this one by a mother of a child with autism:

I'm just thoroughly and continually amazed and appalled at the lack of information that the professionals have on autism.... there's no specific training on autism for the psychologists that [sic] are rating the assessments and providing recommendations that often drive the IEP instruction.

Regarding programming issues, parents of school-age children described a concern about the lack of adequate transition planning and implementation, whereas parents of grown children described an utter lack of services. One mother described how her home state, after denying her funding proposals to keep her school-age son at home, ended up paying for an exorbitantly expensive out-of-state placement:

We had been told by the bureaucrats that the supports would be provided to bring our son home. But when we presented how much that would cost in terms of providing supports, the bureaucrats laughed at us and said, "No way." And in the end, the only placement available is ...600 miles away, at a cost much greater than it would have been to provide the supports we're asking for at home.

Families also described negative practices. One participant noted that she had rejected the school's suggestion that she use Tabasco sauce as a punishment for her daughter. Three of six participants in one focus group mentioned that their children had been abused by professionals paid to provide support.

Friends' comments regarding inadequate school and adult service programs centered on the large number of staff persons providing support. Friends viewed this large number, combined with the high turnover rate among staff, as very problematic:

She's [the friend with challenging behavior] at a bit of a disadvantage, because she has three different people come in to work with her in a 24-hour period, which is very difficult for her. It has appeared to me that she kind of has to change her personality to fit with whomever might be coming in for the next shift. And not only that, but she also has to come to terms with the people who are working with her roommate.

As no participants in the individuals with disabilities focus groups were still in school, their comments regarding inadequate school and adult service programs were limited to the latter. At the time the study was conducted, all participants lived either independently, with their parents, or in community-supported living arrangements.

Those who had lived in institutions were severely critical of their lives there. Those living independently or with their parents expressed no dissatisfaction with their living situations, but those living in community-supported living arrangements saw room for improvement. Their comments concentrated on issues relating to personal freedom and individualization of services. For example, individuals with disabilities described being bothered by circumstances in their apartment living situations caused by roommates and staff who were not chosen by them but assigned. Participants described noise (e.g., the radio being played too loudly, a telephone that was "constantly ringing," a roommate who talked too much) as an issue. Lack of personal freedom was also described in terms of lack of privacy and of being told what to do in their own homes:

I don't like people comin' in my room and tellin' me what to do, saying "Well, you should do this, and you should do that [mimics authoritarian voice]." I said, "Hey, hey now, stop! Don't tell me what to do [voice becomes emotional], please! That makes me mad."

Another individual with a disability questioned the lack of variety in his life, both in terms of support persons and environments:

I been around N.[support person] too much. I just [pause], see, I see N. every day, and I get sick of seein' N. most every day. I want to see different people besides him all time....I want to see different people.... If I could go down to [resort town] and go see Johnny Cash, Merle Haggard, Buck Owens, Roy Clark, Grandpa Jones, and Minnie Pearl...I'd be a lot happier...if I got away from [names the town where he lived], cause it's not the people. I would just like to get away from the whole situation.

Teacher comments regarding inadequate school and adult service programs were clustered around the lack of teacher support to successfully teach the number of students with behavioral challenges, a number they perceived to be growing. Lack of support, in turn, created an additional barrier-waning teacher morale. Teachers described the lack of support in terms of lack of training and resources. Participants described state requirements regarding preservice and inservice training in behavior management as varied, but all of them noted that their preservice training was either inadequate or completely missing. A minority of participants had benefitted from inservice training in positive behavioral support but described this training-although extremely useful-as voluntary and not available on an ongoing basis to other teachers in their districts. Teachers also mentioned frustration at the lack of money and time available to provide their students with an adequate education. At the same time, they commented on the

increased responsibility their districts placed on them to include students with disabilities in their classrooms and on the inflexibility of these districts in seeking real solutions. Participants described how their districts tried to “get around” inclusion by creating situations teachers described as “babysitting at the back of the room.”

Additional Barriers Faced by Support Persons

These types of barriers are additional physical and psychological challenges caused by the interaction between the intensity of support needed and the availability of support persons to meet that need. In other words, where the intensity of support needed by a person with challenging behavior was great and availability of support for support persons (e.g., parent, teacher, friend) was lacking, an additional barrier existed. These barriers were faced by teachers, parents, and friends and fell into two categories: the support person’s own need to be supported physically, and his or her need to be supported emotionally.

Teachers described how lack of training and adequate resources had the effect of creating even more barriers for them to overcome. They often described either themselves or their colleagues as being physically and emotionally drained. Feeling that they were not teaching but “dealing with behaviors all day long,” teachers stated that their colleagues were “looking forward to retirement...counting the years...looking at sabbaticals...looking at maternity leaves, and...looking at all kinds of reasons to get out.”

These barriers were most evident for families and friends. Faced with the responsibility of providing ongoing support when professionals and organizations didn’t, wouldn’t, or couldn’t, families and friends also described physical and emotional support needs. Parents in particular noted the increased physical demands resulting from inadequate school and/or adult programming. As an illustration of the physical impact parents experienced, one mother described a bleak period in which her son was peeling his fingernails off

He was thrown out of school, and I was pretty much one- on-one with him alone 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 care he needed.

Other parents mentioned paying for summer programs themselves or facilitating friendships for their children. In all cases, parents described how they oversaw and facilitated the majority of support activities for their children. For example, one family stated that they drove their son and his 16-year-old friends to the mall, sometimes supporting the entire outing financially and always staying close by:

Sometimes his behavior can be a little unpredictable, too, if he gets nervous or excited....He needs a little assistance in the bathroom and they’re [the friends] not real comfortable with that....They’ll [the friends] push his chair and we can leave him alone for a while, but they kind of want us, I guess, in close enough proximity to support him.

Another mother listed problems posed by the increased size and strength of her daughter, such as difficulties in getting her large daughter to take baths and go to her new adult program. On days when her daughter refused to get out of the car, this mother said that she drove around the entire day with her daughter.

Finally, both families and friends described the emotional impact caused by the combination of challenging behavior and lack of support. Included were examples of stress-producing behaviors, stress-producing reactions by friends and strangers, and the desperation and loneliness caused by being their child's/friend's sole advocate and source of ongoing support.

Just setting up the professionals to come provide all these therapies, it seems like that's a full-time job in itself, and ...it seems to me at some point...that we could go to the bureaucrats and say, "Look, this is what my son needs. Isn't there a way we can provide them?" It just seems overwhelming, and after years and years of fighting the bureaucracy, and looking for services, and trying to get someone to listen, that we run out of energy after a while.

RESEARCH QUESTION 2-POSITIVE, PRACTICAL SOLUTIONS

Three major themes emerged across three or more stakeholder groups regarding successful techniques or approaches: positive behavioral support, "good people," and friendships.

Positive Behavioral Support

Although positive behavioral support of various types was described as a successful strategy by all five stakeholder groups, the majority of the comments were contributed by families, friends, and teachers. Comments clustered around three subthemes: skill building for the person with the disability; skill building for parents, professionals, and support persons; and systems/environmental changes and/or adaptations.

In discussing skill building for persons with disabilities, families and friends described teaching particular skills to replace the challenging behavior. They also described a variety of other empowerment skills:

- academic (e.g., reading and applying for jobs)
- recreation and leisure (e.g., swimming, art, and horseback riding)
- functional (e.g., taking medicine)
- communication (e.g., learning to use a communication device)
- coping (e.g., stress reduction, relaxation, problem solving)
- social

One individual with challenging behavior described the results of conflict-resolution instruction:

MODERATOR: What about when people change the TV channel on you when you're watching a program? Does that bother anybody?

PARTICIPANT: It kind of bothers me sometimes. Kind of makes me mad sometimes.

MODERATOR: How do you handle that?

PARTICIPANT: Oh, just like a man.

MODERATOR: Okay. What does a man do?

PARTICIPANT: He just-he tries to talk it out ... like a mature man.

In describing skill building for parents, professionals, and other support persons, the families, friends, and teachers described pre- and inservice training and other forms of informal, incidental, or self-directed learning. Participants listed as important the following areas:

- learning about conducting functional assessments
- determining learning styles
- establishing trust and rapport
- developing emergency plans
- developing person-centered plans
- delivering positive reinforcement
- becoming communication partners for persons lacking speech.

Learning to read body language was a skill friends noted as very important:

I agree with all the participants that my friend, his body- language communication was much more important than what the words were. Just being able to read him, body- language-wise, was real important because the words would not always follow the body movement.

Finally, in describing systems or environmental changes or adaptations, families, friends, and teachers mentioned the following items:

- changing programs (e.g., changing class sizes and staffing ratios)
- establishing predictable schedules based on individual preferences
- providing both traditional (e.g., occupational and physical) and nontraditional (e.g., horseback riding) therapies
- adopting diets
- reducing medication levels
- including persons with challenging behavior in “normalized” settings
- respecting environmental changes initiated by the person with challenging behavior (e.g., allowing a person to leave a smoke-filled room),
- using humor to lighten tense situations.

For example, one friend described using humor when he and the person with disabilities ran out of gas for their small boat in the middle of a lake:

Last summer we were standing in a boat out in the middle of nowhere for about 4 hours, and that’s a very tense situation, too, for this guy, because he couldn’t control what happened...and the fact that we were able to turn it into a joke-that we’re never going to be found and we’re stuck here forever-really helped him get through that problem ... all of a sudden it was funny to him, that we were watching the fish swim by....That took a situation where he was definitely headed for a problem and...turned it into a more upbeat, fun thing.

Good People

“Good people” were described by all stakeholder groups as individuals (vs. systems or programs) who, on their own, went above and beyond what was necessary or required to provide free and appropriate public education and/or an increased quality of life for individuals with challenging behavior. These good people were family members, friends, support persons, or teachers who were persistent, flexible, and caring. They were also described as proactive people who questioned the appropriateness of certain strategies, used crisis as a catalyst for change, and celebrated achievements. Good people seemed to be the critical link in initiating and maintaining social, educational, and behavioral improvements in the lives of persons with disabilities and challenging behavior. Although finding good people is not, strictly speaking, an approach or technique, what good people did facilitated the solutions that the participants experienced. Descriptions ranged from general classes of good people given by administrators and policy makers to descriptions of specific people or actions taken by families, friends, and teachers.

One of the administrators gave an example of the former:

I find repeatedly people who come into their profession ... with high expectations of working with kids, loaded with values, tremendously interested in doing a very good job and whenever they feel that they can make a positive difference, then that's a reward to them.

One person described a strategy she used in helping facilitate relationships for her friend with the challenging behavior:

I talk about my friend in social situations, as far as the fun things that we do and how much fun she is. And so they seem more excited to meet her than nervous. They, you know, they think that she's fun because of the way I talk about her and that she's a fun person to be around, and they don't see her as a challenge.

Friendships

Friends, families, and persons with disabilities were the only groups who commented on friendship. Although the categories of friendships and good people have much in common and are not meant to be mutually exclusive, friendships can be distinguished from good people in a number of important respects. First, although all participants who maintained friendships with individuals with challenging behavior could also be classified as good people, not all participants whom researchers described as good people maintained friendships with individuals with challenging behavior. For example, although a teacher might have been instrumental in initiating and maintaining a positive behavioral support plan for students (and hence would be regarded as a “good person”), he or she might not have regarded him- or herself as a friend. Second, friendship was limited (by the criteria established for the study) to relationships that (a) included reciprocal giving and receiving, (b) occurred over time, and (c) exceeded the “pay for service” kind of arrangement. For example, friends participated in a range of mutually satisfying activities across a variety of environments without financial remuneration:

We do a lot of stuff at school. I do her makeup, she does my makeup. We do hair, we paint nails. I went to her birthday party. We play outside at recess and we watch *America's Most Funniest Videos* and laugh a lot.

Friends did not limit their participation to a particular environment (e.g., a classroom) or a particular type of activity (e.g., a therapy session). Further, their relationships did not end when they or their friends with challenging behavior moved to a different classroom or a different part of town. Finally, friendships were characterized by a person “sticking with” an individual through challenging periods:

We [she and her friend] experienced some very, very, challenging behaviors right after I first started hanging out with him. And once we kind of got through that really difficult time and that we really hung in there and stuck together, you know, I felt like we developed more of a friendship.

A third important reason for distinguishing the idea of friendship from that of good people lies in the potential importance of further examining friendship facilitation more closely as a strategy for reducing challenging behavior. The common denominator that linked the strategies of persons who described themselves as friends was an established personal relationship with the individual with challenging behavior. One participant described how developing a number of conversational routines as part of his friendship was also helpful in easing tensions:

We have some stock things that we do, whether it’s reiterating back to each other a scene from a movie, or we have a couple of stock conversations that we’ll have. I think that we’ve had them an infinite number of times, but it’s always fun to have them over again....so going back to something that we have done before that has been successful is another way that we’ve found that, you know, we get along better and can ease some stressful situations.

RESEARCH QUESTION 3- USEFUL INFORMATIONAL PRODUCTS

The need for positive and practical information, which is essential for successful techniques or approaches, also emerged as a principal theme. Two subthemes most often discussed across all five stakeholder groups regarding such products were (a) type of information and (b) form of the information.

Type of Information

Type of information described the topic or content area the information should address. Although all stakeholder groups had comments about this area, comments by administrators and policy makers were fewer in number and more general in nature, whereas comments made by other stakeholder groups were greater in number and more specific in nature. Administrators and policy makers mentioned only that information on prosocial behavior was necessary. Individuals with disabilities and friends stressed the need for more positive information that emphasized similarities rather than differences among people and the contributions made by persons with disabilities. Friends, for example, stressed the importance of generating a “relationship profile” that described a person’s preferences, likes, and dislikes. Friends also stressed the need for (a) experiential kinds of information that would allow them to actually see someone effectively supporting an individual with challenging behavior and (b) information on friendship facilitation:

I think one of the biggest things...and also one of the hardest, is just trying to find new friends. I would love to have information... on how to do that.

Of all the groups, families had the greatest number of specific suggestions about the type(s) of information they felt was needed. Their suggestions ranged from information on functional assessments of behavior to specific types of therapy (e.g., sensory integration therapy) to information on mood swings to the effects of various kinds of diets (e.g., gluten- and casein-free). Teachers suggested needing information on multicomponent, long-term, positive behavioral approaches and short-term information on what to do in a particular situation. For example, they suggested a need for skill and awareness- level training in positive behavioral support as well as manuals that pinpointed specific behaviors and provided them with step-by-step instructions on what to do.

Form of Information

All stakeholder groups also commented on informational formats. Administrators and policy makers mentioned interactive television and video conferencing as useful for training teachers. Families, friends, and teachers all wanted to receive information in a person-to-person format from “veteran” families, friends, and teachers who knew firsthand the practical limitations of supporting an individual with challenging behavior in typical home, school, and community contexts:

I was really fortunate when I first started. I had many people that [sic] were also involved at the same time that I was jumping in that I was able to model off of, and it was usually a structured time when myself, my new friend, and usually someone with not only experience, but some good education behind, and was able to model behaviors for me or to guide me in a certain way as to what I should do...so it was really quite a bit easier for me and I really consider myself lucky....In the first months that’s the way it worked out.

Similar to families, friends, and teachers, individuals with disabilities expressed a preference for receiving information in a person-to-person way from someone they knew and trusted. Families, friends, and teachers were less than enthusiastic about written information. They all agreed that any written material needed to be short and formatted in an easy-to-read manner.

Discussion

STUDY LIMITATIONS

Limitations of this study include (a) cautions about making generalizations based on participant comments or frequencies presented and (b) possible sources of researcher bias. The purpose of this study was not to make sweeping statements about challenging behavior or the perspectives of various stakeholder groups. Rather, the primary purpose was to give voice to 59 participants from five stakeholder groups in an attempt to better understand their experiences and perceptions of challenging behavior exhibited by individuals with mental retardation and/or autism. Although we sought participants nationwide from approximately 40 sources and were careful to select participants who met both general and stakeholder group- specific screening criteria, these participants may have been uncharacteristic of the stakeholder groups they represented. Further, although we conducted a total of 10 focus groups (59 participants), only two focus groups were conducted per stakeholder group. This may have resulted in important categories not emerging or relationships between categories remaining unclear. Given the qualitative and exploratory nature of the study, we want to emphasize the importance of viewing listings of frequencies (see Table 3 for the frequencies of the three major themes by stakeholder group) as

descriptive of participant experiences or perceptions regarding the challenging behavior of individuals with autism and/or mental retardation but not as evidence of statistical significance. Finally, although the data were read and analyzed separately by two researchers and their findings were later confirmed by a third researcher not involved in the study, it is possible that researcher bias could have mediated the identification of themes.

KEY THEMES

Given the exploratory nature of this study, we were careful not to draw definitive conclusions. However, issues that emerged within the themes-values, best-practice solutions, new directions in providing solutions, supporting support persons, and useful information-merit some attention.

Values

Underlying the idea of providing support to individuals with mental retardation and/or autism who exhibit challenging behavior is the question of whether or not these individuals are valued or dehumanized. Although mentioned by every group, fewer lines were spoken relative to values than to any other issue. Number of lines alone cannot be considered meaningful (and may be due partly to the general nature of the research questions), but this might reflect the lack of answers participants had for the question of how to remove the dehumanizing values described by all participants as existing in society and the bureaucratic systems.

Data such as those compiled by Stephens, Lakin, Brauen, and O'Reilly (1990), which suggested that more than half the students with disabilities placed in separate residential schools exhibited challenging behavior may support the idea of dehumanizing values described by focus-group participants. Although these data present a picture regarding the extent of the problem of restrictive placements, they tell us little about the values or the criteria on which decisions and the decision-making process are based. Important for all stakeholder groups would be a clearer picture of which groups value what. Especially important in this regard would be clarifying the values of administrators and policy makers. The division that emerged among members of this stakeholder group on the issue of placement of individuals with challenging behavior in separate, alternative settings indicated a need for values clarification and for demonstrations of how students with challenging behavior can be proactively supported within the contexts of general education classrooms.

Best-Practice Solutions

Regarding best practice solutions, we found it interesting to note which stakeholder groups contributed the most and which contributed the least. Administrators and policy makers lacked concrete suggestions, but families, friends, individuals with disabilities, and teachers contributed many of them. Of these four groups, families, friends, and individuals had the most proactive solutions.

Administrators and policy makers provided little detail regarding behavioral support. In 3 hours of discussion, for example, only a single reference was made to a book on behavioral support. Successful programs were mentioned by name, but no methodological detail was presented on how teachers and others could be successful in supporting students with behavior challenges. Although they expressed interest in hearing about model programs mentioned in the course of the focus groups, few administrators and policy makers had specific information about best practices aimed at supporting persons with

challenging behaviors in home, school, and community environments. As these individuals' orientations have a profound impact on the delivery of support services, it was distressing to note that they failed to talk about how students with challenging behaviors could be supported (the array of support options available), instead concentrating on where students with challenging behaviors should be educated.

We also were struck by the seeming lack of connection between best practices as illustrated in the literature and day-to-day practice in schools. For example, not one teacher mentioned student difficulties with communication and how they were overcome. No teacher mentioned adapting instruction to meet the needs of students with disabilities and challenging behavior. Most teachers, however, described how they used token economies and various reactive strategies such as time-out. The obvious question this seeming gap between research and practice raised was, "Why wasn't there more description of best practices?"

In contrast to the lack of input by administrators and the limited range of solutions offered by most teacher participants, evidence of the range of proactive strategies currently available was given by families, friends, and individuals with disabilities. Families, friends, and a minority of teachers described examples of environments being adapted and of enviable lifestyles being created for individuals with challenging behaviors.

Although we are extremely cautious in giving meaning to frequencies, it was interesting to compare the ratio of statements coded by stakeholder groups as barriers to those coded as solutions. Administrators and policy makers generated nearly three times as many barriers as solutions (1: .38) and families and teachers generated roughly equal numbers of barriers and solutions (1: .92); however, friends generated roughly twice as many solutions as barriers (1:2.24) and individuals with disabilities generated nearly three times as many solutions as barriers (1:2.76). Administrators and policy makers thus seemed more focused on barriers, whereas individuals with disabilities and friends seemed more focused on solutions (see Table 3).

Information on how to successfully support individuals with challenging behavior is available. Administrators and policy makers, teachers, and other groups paid to provide leadership and support *should* be the best informed about best practice solutions. Further research is needed to determine if the lack of description regarding best practices by participants in this study is reflective of an overall lack of knowledge regarding such practices by a more representative sample of administrators, policy makers, and teachers.

Quality of Life

Creating comprehensive lifestyle change for individuals with challenging behavior emerged as an issue worthy of further exploration. *Quality of life* is defined from the subjective standpoint of the individual (Gardner, Nudler, & Chapman, 1997; Hughes & Hwang, 1996; Schalock, 1996, in press) and reflects outcomes for people rather than compliance with a program process (Borthwick-Duffy, 1996; Gardner & Nudler, 1997). Individuals with mental retardation and/or autism who exhibited challenging behavior and were living in agency settings described how quality-of-life improvements were rarely individualized or reflective of outcomes they had chosen. Their lives seemed to be missing individualized personal outcome measures grounded in the principle of informed decision.

There was no discussion of (a) individuals with disabilities defining their own outcomes, (b) individuals with disabilities experiencing a range of options from which to make choices, or (c) organizations facilitating outcomes identified by these individuals (Gardner et al., 1997); instead, participants discussed the frustrations of not being able to self-select apartments, roommates, and vacations. They also noted their desire for increased social and friendship connections. Although individuals with disabilities living in agency-run group homes and apartments described improvements in various quality-of-life domains (in contrast to their earlier experiences in state institutions), the message they conveyed was that they wanted more control in determining their own quality-of-life outcomes. Indeed, these individuals did not view themselves so much as “behavior problems” as they did individuals whose lives were missing the key critical elements that make up an individualized, comprehensive lifestyle. Their statements appeared to confirm that their challenging behavior emerged from a background of exclusion, lack of personal control, and unenviable lifestyles. Finally, their statements suggested that current programs and restrictive placements-not the individuals-were the problems to be “fixed.” Because there are very few studies that document the effects of quality-of-life improvements in reducing or eliminating challenging behavior (Carr et al., 1997), additional research is needed regarding the effect of a coordinated, comprehensive effort to provide preference-based lifestyle support. By targeting families and friends who have succeeded in creating such comprehensive support, much can be learned about practical, positive solutions.

The administrators and policy makers stakeholder group and the teacher group did not address the topic of quality of life. One could argue that administrators and policy makers are too far removed to grasp the full importance of this issue, but one could also argue that this group, in particular, should be most cognizant of quality-of-life issues, if only from the standpoint of fiscal implications. Research conducted by Bellamy, Newton, LeBaron, and Horner (1990) indicated the relative inexpensiveness of providing for quality-of-life improvements as compared to other types of supports.

Despite their daily involvement, teachers said little about quality of life. Members of this group reported difficulty in managing their current responsibilities and that they had no time to deal with such issues as facilitating friendships. They referred to students more as members of a group than as individuals. Teachers may be too busy or may not view quality-of-life issues as their responsibility. There is, however, increasing evidence to suggest that schools should consider the quality-of-life area of social and emotional relationships. Falvey and Rosenberg (1995) and Strully and Strully (1996), suggested that friendships be considered as educational goals. Other researchers have suggested placing more emphasis on belonging and socialization as a method for improving overall quality of life (O’Brien & O’Brien, 1992; Van der Klift & Kunc, 1994).

The contrast between friends’ positive attitude and teachers’ frustrations in supporting individuals with challenging behavior was striking. Friends saw their peers with disabilities as persons first. They worked proactively, albeit without bureaucratic constraints, to prevent challenging behavior from occurring. Person-centeredness permeated their discussion.

Based on this study’s findings, researchers might explore the relationships between the quality-of-life domain of social and emotional relationships and the issue of challenging behavior. Why was the idea of quality-of-life improvements absent in discussions with the administrators and policy makers group and the teacher group even though it formed the heart of the conversations with individuals with disabilities,

their families, and friends? Why did friends succeed in increasing the number and quality of activities in home and community settings? Additional research is needed to explore the effect of providing teachers with both the information and the supports necessary to address such aspects of quality of life as the facilitation of social and emotional relationships among students with challenging behavior. Further, as no one knows more about their quality of life than the persons with challenging behavior themselves, additional research should be specifically aimed at giving voice to these individuals.

Supporting Support Persons

Although the need to assist support persons was a theme that echoed strongly among every stakeholder group involved in providing hands-on support to individuals with challenging behavior (i.e., families, friends and teachers), few comments were made by administrators and policy makers about this vital issue. The comments that members of this group did offer were in relation to teachers only and mainly addressed the question of resources (i.e., the time and money needed to provide more information and training). There is a need to explore broader definitions of support such as those proposed by Adelman and Taylor (1997) that encompass establishing in schools a primary, essential “enabling” component specifically aimed at addressing learning barriers by weaving together school and community resources.

Why was the discussion by those in a position to make positive changes so limited? This lack of discussion is particularly telling when one considers the success experienced by the friends—the only group where all participants described receiving support. Although there are noticeable differences between the role of a friend and that of a teacher (e.g., the limited amount of time teachers could spend one-on-one, the limitations imposed on teachers by the curriculum and other school regulations, or the lack of reciprocity in many teacher-student relationships), much can be learned from the successes achieved by friends in minimizing and/or eliminating episodes of challenging behavior. Additional research is needed to identify the factors that allowed friends (and some teachers) to successfully provide ongoing support to individuals with challenging behavior. Such research should identify ongoing support needs of both the individuals with challenging behavior and their support persons.

Useful Information

The gap between research and practice was nowhere more evident than in the comments made about useful information. Although all groups agreed on the importance of increased and easy access to research-based information, the groups providing the most direct support (families, friends, and teachers) questioned the relevance of research and the usefulness of the form in which it is disseminated. Members of these groups emphasized they had neither the time nor the desire to take a general-to-specific approach in which support persons are left to interpret how a published research study might be applicable to a particular situation. They did not want to become behavioral support experts: teachers wanted to teach and families and friends wanted to make quality-of-life improvements for the individual they supported. In this regard, they found information provided directly in the form of mentoring by another “veteran” family, friend, or teacher most helpful. Families, friends, individuals with disabilities, and teachers described rapport and trust as essential prerequisites to accepting information. They described trust and rapport as easier to achieve with “veterans” who had not only successfully supported individuals with challenging behavior but had done so under the constraints of time, energy, and resources typically experienced by families, friends, and teachers. All members of the families and friends groups, and 11 of

12 teachers, stated that they had little time to read. They thus recommended that written information be attractively formatted in easy to understand language and that it not exceed 2 pages.

In contrast to the emphasis given to mentoring by families, friends, and teachers, the administrators and policy makers did not mention it. Further, they did not address the question of what specific types of information and dissemination would be useful, either to themselves or to other constituency groups. Their remarks were limited to a general discussion of the need for better preservice and inservice behavioral support training for teachers. Additional research studies are needed to explore the impact of providing research-based information in preferred formats to stakeholder groups. Further, administrators, policy makers, and researchers need to answer the question of who is responsible for guaranteeing that federal- and state-funded research is not only disseminated but also utilized by persons providing direct support.

Conclusion

The unique-and potentially valuable-contribution of this research study is in the convergence of divergent perspectives on challenging behavior. While analyzing and reporting the findings of administrators and policy makers, families, friends, individuals with mental retardation and/or autism who exhibited challenging behaviors, and teachers, it was easy to become lost in details and lose sight of the overall implications. In presenting the most relevant implications of this study in the briefest possible way, we rely on a quotation by Stephen Covey (1990), "Seek first to understand, then to be understood" (p. 235). The difficulty of putting this statement into practice was reflected by the focus group data. It became clear in reading the transcripts that no one stakeholder group had a good understanding of the issues the other groups considered important. Although there were differences in the alignment between particular groups, for all of them it was obvious that not enough understanding has occurred between and among them. This may be the most important finding of this study.

If the underlying assumption on the part of all stakeholder groups is a desire to provide comprehensive, preference-based lifestyle support for persons with mental retardation and/or autism while reducing or eliminating the challenging behavior that they experience, then the voices of those most intimately connected with that behavior-the individuals themselves, their families, and their friends-must be better understood by administrators, policy makers, and teachers.

NOTE

Readers who would like more detailed demographic data may contact the authors.

Table 1. General Eligibility Criteria and Individual Stakeholder Group Criteria

Term	Description
General eligibility criteria	<p>Any serious episode of the type that required direct intervention, such as physical restraint, and in which there was a potential for serious damage to self, others, or property. Examples include (a) self-injurious behavior – hurt oneself by banging, hitting, biting, or ingesting foreign and nonedible substances; (b) physical aggressiveness – hurting others by hitting, choking, pulling hair, or biting; (c) property destruction – destroying furniture, clothes, or objects.</p> <p>Engagement in the types of behaviors described above <i>or</i> provision of support to individuals engaged in behaviors similar to these as defined by stakeholder group criteria.</p>
Stakeholder group screening devices Administrators and policy makers	<p>Hold a leadership position in a school district or agency with ability to influence policy and procedures affecting services for individuals with challenging behavior and mental retardation and/or autism, their families, and/or support personnel.</p>
Families	<p>Considered to be part of the family of an individual with challenging behavior and cognitive challenges and/or autism by other members of that family. Live with an individual with challenging behaviors and cognitive challenges and/or autism or play role equivalent to an in-home family member in providing support.</p>
Friends and peers	<p>Be a minimum of 13 years old. Maintained friendship for 1 year or more. Consider self to be a “friend” of a person with challenging behaviors and cognitive challenges and/or autism. Consider relationship to be reciprocal in nature (i.e., relationship exceeds “pay for service” kind of arrangement).</p> <p>For purposes of this study, a “peer” is someone who is approximately your age and whom you see together with others on a regular basis, but with whom you don’t necessarily arrange to do things apart from a group. Classmates, fellow band members, and members of a church or synagogue group could all be considered peers. Peers can be of either gender. Consider self to be a “peer” of a person with challenging behaviors and cognitive challenges and/or autism.</p>
Individuals with disabilities	<p>(See general eligibility criteria). Be a minimum of 13 years old.</p>
General and special education teachers	<p>Support at least one individual with challenging behavior and cognitive challenges on a weekly basis. In this context, <i>support</i> means being responsible for planning and implementing the individual’s instruction or daily living activities for 2 or more hours a week.</p>

Table 2. Description of Research Question Subthemes That Appeared Across Three or More Stakeholder Groups

Theme	Stakeholder Group	Description
Barriers regarding challenging behavior		
Impact of societal values	All groups	Describes practices as reflective of societal values, specifically to the value or lack of value that society places on (a) persons with disabilities and challenging behavior, (b) persons with disabilities in general, and (c) education. Includes discussion of labels, staff/program/community awareness, knowledge, and tolerance regarding persons with disabilities.
Inadequate school/adult service programs	All groups	Refers to program(s) unable to provide sufficient individualized support that results in sufficient progress toward goals for all students (e.g., successful transition to adulthood; increased social interaction). Includes discussion of (a) lack of administrative support, (b) staff/agency inflexibility, (c) use of aversive procedures, and (d) program access.
Additional barriers faced by support persons	Families, friends, individuals with challenging behavior, teachers	Describes barriers that make supporting a person with mental retardation and/or autism who exhibits challenging behaviors particularly difficult for support persons. Includes barriers faced by person who are friends and by persons who fall in the “grey area” between “acquaintance” and “friend.” Includes discussion of (a) resources, (b) single parents, (c) emotional reactions of support persons, (d) conflict in childbearing philosophies, (e) communication, (f) responsibility, and (g) separation.
Positive and practical solutions to challenging behavior		
Positive behavior support	Families, friends, teachers	Refers to positive behavior support as it applies to (a) solutions that focus on the person with disabilities learning new skills and (b) solutions that focus on support persons learning the skills required to proactively support an individual with challenging behavior.
Good people	All groups	Refers to the differences individuals (vs. systems) can make. Includes descriptions of what individual teacher/family member/support person/friend did that was above and beyond what was necessary or required. Includes descriptions of changes effected within classrooms and other environments to provide free and appropriate education in the least restrictive setting and/or to increase quality of life for a person(s) with a disability.
Friendships	Families, friends	Refers to relationships involving reciprocity and exceeding “pay for service” kinds of arrangements. Includes types of activities shared, how relationship developed, positive effects of friendships, and friendship facilitation.
Information and informational products useful in building positive, practical solutions to challenging behavior		
Type of information	All groups	Refers to the topic or content of information. Includes informational sources, areas for future research, and how information should be “slanted” for particular stakeholder groups.
Form of information	All groups	Refers to formats for producing/receiving information. Includes medium, length, and other characteristics.

Table 3. Frequencies of Coded Transcript Segments by Major Themes and Stakeholder Groups

Group	Barrier^a	Solution^b	Information^c
ADM/POL1*	33	15	9
ADM/POL2*	58	20	13
FAMILIES1	94	85	15
FAMILIES2	63	59	28
FRIENDS1	33	67	31
FRIENDS2	29	72	50
INDIVIDUALS1*	23	48	4
INDIVIDUALS2*	15	57	5
TEACHERS1*	34	19	32
TEACHERS2*	21	25	17

*Note. ADM/POL = Focus group consisting of administrators and policy makers; INDIVIDUALS = Focus group consisting of individuals with mental retardation and/or autism who exhibit challenging behaviors; TEACHERS = Focus group consisting of teachers and practitioners; 1 & 2 = First and second focus groups conducted.

^abarriers regarding challenging behavior.

^bpositive and practical solutions aimed at reducing or eliminating challenging behavior.

^cInformation and informational products useful in building positive, practical solutions to challenging behavior.

REFERENCES

- Adelman, H. S., & Taylor, L. (1997). Addressing barriers to learning: Beyond school-linked services and full service schools. *American Journal of Orthopsychiatry*, 67, 408-421.
- Alberg, J. (1992). *A decision tool for administrators: Integrating children with disabilities into the mainstream*. Denver, CO: Sopris West.
- Alberto, P. A., & Troutman, A. C. (1990). *Applied behavior analysis for teachers* (6th ed.). Columbus, OH: Merrill.
- The Association for Persons with Severe Handicaps. (1981). *Resolution on intrusive interventions*. Seattle: Author.
- Behavioral Interventions for Special Education Students, 5 C.F.R. § 3001 (1993).
- Bellamy, G. T., Newton, J. S., LeBaron, N., & Horner, R. H. (1990). Quality of life and lifestyle outcomes: A challenge for residential programs. In R. L. Schalock (Ed.), *Quality of life: Perspectives and issues* (pp. 127-137). Washington, DC: American Association on Mental Retardation.
- Biklen, S. K., & Moseley, C. R. (1988). "Are you retarded?" "No, I'm Catholic": Qualitative methods in the study of people with severe handicaps. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 155-162.
- Billingsley, B. S. (1993). Teacher retention and attrition in special and general education. A critical review of the literature. *The Journal of Special Education*, 27, 137-174.
- Billingsley, B. S., Bodkins, D., & Hendricks, M. B. (1993). Why special educators leave teaching: Implications for administrators. *Case in Point*, 7(2), 23-40.
- Billingsley, B. S., & Cross, L. H. (1991). Teachers' decisions to transfer from special to general education. *The Journal of Special Education*, 24(4), 496-511.
- Borthwick-Duffy, S. A. (1996). Evaluation and quality of life: Special considerations for persons with mental retardation. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Volume I. Conceptualization and measurement* (pp. 105-120). Washington, DC: American Association on Mental Retardation.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46(6), 722-730.
- Brotherson, M. J. (1994). Interactive focus group interviewing: A qualitative research method in early intervention. *Topics in Early Childhood Special Education*, 14(1), 111-118.
- Brotherson, M. J., & Goldstein, B. L. (1992). Quality design of focus groups in early childhood special education research. *Journal of Early Intervention*, 16, 334-342.
- Carnine, D. (1997). Bridging the research-to-practice gap. *Exceptional Children*, 63(4), 513-522.

- Carr, E. G., Horner, R. H., Turnbull, A. P., Marquis, J. G., Magito-McLaughlin, D., McAtee, M. L., Smith, C. E., Ryan, K. A., Ruef, M. B., & Doolabh, A. (1997). *Positive behavioral support as an approach for dealing with problem behavior in people with developmental disabilities: A research synthesis*. Unpublished manuscript, State University of New York at Stony Brook.
- Chesler, M. (1991). Participatory action research with self-help groups: An alternative paradigm for inquiry and action. *American Journal of Community Psychology*, 19, 757-768.
- Covey, S. R. (1990). *The 7 habits of highly effective people: Powerful lessons in change*. New York: Simon & Schuster.
- Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- Denzin, N. K. (1978). *Sociological methods*. New York: McGraw-Hill.
- Falvey, M. A., & Rosenberg, R. L. (1995). Developing and fostering friendships. In M. A. Falvey (Ed.), *Inclusive and heterogeneous schooling: Assessment, curriculum, and instruction* (pp. 267-283). Baltimore: Brookes.
- The Family Connection staff, DeVault, G., Krug, C., & Fake, S. (1996). Why does Samantha act that way? *Exceptional Parent*, 26 (9), 43-47.
- Gardner, J. F., & Nudler, S. (1997). Beyond compliance to responsiveness: Accreditation reconsidered. In R. L. Schalock (Ed.), *Quality of life: Vol. II. Application to persons with disabilities*. (pp. 135-148). Washington, DC: American Association on Mental Retardation.
- Gardner, J. F., Nudler, S., & Chapman, M. S. (1997). Personal outcomes as measures of quality. *Mental Retardation*, 35, 295-305.
- Guess, D., Helmstetter, E., Turnbull, H. R., & Knowlton, S. (1987). *Use of aversive procedures with persons who are disabled: A historical review and critical analysis*. Seattle, WA: The Association for Persons with Severe Handicaps.
- Horner, R. H., Albin, R. W., & O'Neill, R. E. (1996). Supporting students with severe intellectual disabilities and severe challenging behaviors. In G. Stoner, M. R. Shinn, & H. M. Walker (Eds.), *Interventions for achievement and behavior problems* (pp. 269-287). Bethesda, MD: National Association of School Psychologists.
- Hoshmand, L. T., & Polkinghorne, D. E. (1992). Redefining the science- practice relationship and professional training. *American Psychologist*, 47 (1), 55-66.
- Hughes, C., & Hwang, B. (1996). Attempts to conceptualize and measure quality of life. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Volume I. Conceptualization and measurement* (pp. 51-62). Washington, DC: American Association on Mental Retardation.
- Kaestle, C. F. (1993). The awful reputation of educational research. *Educational Researcher*, (1), 3223-31.
- Kaufmann, J. M., Schiller, E., Birman, B., & Coutinho, M. (1993). A federal perspective on improving practices, programs, and policies in special education. *Evaluation and Program Planning*, 16, 263-269.

- Knodel, J. (1993). The design and analysis of focus group studies: A practical approach. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 35-50). Newbury Park, CA: Sage.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F., & Plienis, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, 22 (2), 203-216.
- Kornblet, A., Billups, L. H., Sydoriak, D., Fields, M. J., Morrisey, P. A., & Mitchell, S. M. (1997). Responses to bridging the research-to-practice gap. *Exceptional Children*, 63, 523-534.
- Krueger, R. A. (1993). Quality control in focus group research. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 65-85). Newbury Park, CA: Sage.
- Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage.
- LaVigna, G. D., & Donnellan, A. (1986). *Alternatives to punishment: Solving behavior problems with non-aversive strategies*. New York: Irvington.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Malouf, D. B., & Schiller, E. P. (1995). Practice and research in special education. *Exceptional Children*, 61, 414-424.
- Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Maxwell, J. A. (1996). *Applied social research methods series: Vol. 41. Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage.
- Morgan, D. L. (Ed.). (1993). *Successful focus groups: Advancing the state of the art*. Newbury Park, CA: Sage.
- Morgan, D. L., & Krueger, R. A. (1993). When to use focus groups and why. In D. L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 3-19). Newbury Park, CA: Sage.
- O'Brien, J., & O'Brien, C. L. (1992). Members of each other: Perspectives on social support for people with severe disabilities. In J. Nisbit (Ed.), *Natural supports in school, at work, and in the community for people with severe disabilities* (pp. 17-64). Baltimore: Brookes.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.
- Quine, L. (1986). Behavior problems in severely mentally handicapped children. *Psychological Medicine*, 16, 895-907.
- Risley, T. (1996). Get a life! Positive behavioral support in people with developmental disabilities. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community* (pp. 425-438). Baltimore: Brookes.

- Robbins, F. R., Dunlap, G., & Plienis, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, 15 (2), 173-184.
- Schalock, R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Volume I. Conceptualization and measurement* (pp. 123-139). Washington, DC: American Association on Mental Retardation.
- Schalock, R. L. (in press). Three decades of quality of life. In M. Wehmeyer & J. R. Patton (Eds.), *Mental retardation in the 21st century*. Austin, TX: PRO-ED.
- Seidel, J., Friese, S., & Leonard, D. C. (1995). The Ethnograph V4.0: A user's guide [Computer software]. Amherst, MA: Qualis Research Associates.
- Silverman, G. R. (1992). *New capabilities improve focus groups* [Report]. Orangeburn, NY: Market Navigation, Teleconference Network.
- Stark, J., & Faulkner, E. (1997). Quality of life across the life span. In R. L. Schalock & G. N. Siperstein (Eds.), *Quality of life: Vol. I. Conceptualization and measurement* (pp. 23-32). Washington, DC: American Association on Mental Retardation.
- Stephens, S. A., Lakin, K. C., Brauen, M., & O'Reilly, F. (1990). *The study of programs of instruction for handicapped children and youth in day and residential facilities*. Washington, DC: U.S. Department of Education and Mathematics Policy Research.
- Stewart, D. W., & Shamdasani, P. N. (1990). *Applied social research methods: Vol. 20. Focus group: Theory and practice*. Newbury Park, CA: Sage.
- Strully, J. L., & Strully, C. (1996). Friendships as an educational goal: What we have learned and where we are headed. In S. Stainback & W. Stainback (Eds.), *Inclusion: A guide for educators* (pp.141-154). Baltimore: Brookes.
- Taylor, S. J., & Bogdan, R. (1984). *Introduction to qualitative research methods: The search for meanings*. New York: Wiley.
- Turnbull, A. P., & Ruef, M. (1997). Family perspectives on inclusive lifestyle issues for individuals with problem behavior. *Exceptional Children*, 63, 211-227.
- Turnbull, A. P., & Turnbull, H. R. (1996). Group action planning as a strategy for providing comprehensive family support. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavioral support: Including people with difficult behavior in the community* (pp. 99-114). Baltimore: Brookes.
- Van der Klift, E., & Kunc, N. (1994). Beyond benevolence: Friendship and the politics of help. In J. S. Thousand, R. A. Villa, & A. I. Nevin (Eds.), *Creativity and collaborative learning: A practical guide to empowering students and teachers* (pp. 391-401). Baltimore: Brookes.