Stakeholder Opinions on Accessible Informational Products Helpful in Building Positive, Practical Solutions to Behavioral Challenges of Individuals with Mental Retardation and/or Autism

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Abstract: The purpose of the study was twofold: (a) to explore the perceptions of administrators and policy makers, families, friends, individuals with challenging behavior and mental retardation and/or autism, researchers, and teachers regarding current behavioral information and dissemination and (b) to elicit suggestions on the kinds of user-friendly, low-cost informational products that they thought would be most helpful in increasing quality of life while reducing or eliminating behavioral challenges in individuals with disabilities. A qualitative method of inquiry using telephone focus groups and individual interviews was used. The study points to the importance of receiving condensed positive behavioral support information on both awareness and skill levels and to the continued existence of a longstanding gap between research and practice, a gap that exists despite the extensive research base on effective dissemination strategies and techniques.

It has been well documented that a gap exists between what educational research and demonstration projects produce and what state and local education agencies practice (Beutler, Williams, & Wakefield, 1993; Billups, 1997; Carnine, 1995a, 1997; Gersten, Vaughn, Deshler, & Schiller, 1997; Hosmand & Polkinghorne, 1992; Malouf & Schiller, 1995; Schwartz, Carta, & Grant, 1996) and may link to researchers' perceived desire to distance themselves from the subjects of their research (Zarb, 1992).

Traditional, top-down educational research (i.e., the researcher defines the problem(s) and plans the solutions and the teacher implements them) has neither produced powerful interventions or has significantly impacted practice (Abbott, Walton, Tapia, & Greenwood, 1999; Cuban, 1993; Gersten, Morvant, & Brengelman, 1995). Kaufman, Schiller, Birman, and Coutinho (1993) describe professional literature as teachers' "stop of last resort," (p. 266)

and Fuchs and Fuchs (1990) state that research itself is viewed by many educators as irrelevant and "conducted primarily for the amusement of researchers" (p. 104).

In counterpoint, many researchers view constituents as non-rational, too practical, or unwilling or unable to read and apply the professional literature (Malouf & Schiller, 1995). Further, some researchers believe that research (i.e., basic research with implications but no direct practical application) is not designed to make a practical difference (Carnine, 1997).

Dissemination too, as practiced by agencies, school systems, researchers and schools systems needs improvement; this despite the literature base on research dissemination and utilization (Fuhrman, 1994; Huberman, 1990; Leung, 1992; Rodgers & Adams, 1994; Westbrook & Boethel, 1997) and on collaboration between researchers and practicioners (Carnine, 1995b, 1997; Billups, 1997; Englert & Tarrant (1995); Fuchs & Fuchs, 1998; Kennedy, 1997; Komblet, 1997). Kaestel (1993) described OERI's ERIC regional lab system, the oldest and largest dissemination system in existence, as suffering from ". . .a widespread verdict of uselessness" (p.27). A growing number of researchers

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have described the traditional professional development model of brief workshops as symptomatic of the field's gross underestimate of the time and effort needed to produce meaningful change in practice (Abbott et al., 1999, Cuban, 1993; Gersten et al., 1995; Woodward, 1993). Dissemination as practiced by many researchers is a way to document research findings rather than actively promote knowledge use. The old analogy that "a better mouse trap doesn't mean people will buy it" also applies in research dissemination and utilization. "Mousetrap" users must be ready to take action, be comfortable with new information, have confidence in its operation, afford it, trust the manufacturer, and believe it is an improvement (National Center for Dissemination of Disability Research, 1996).

Within the field of disability there is a wide gap between what is known and what is effectively communicated to parents of children with challenging behavior (Turnbull & Ruef, 1996, 1997). Individuals exhibiting challenging behavior face a high risk of exclusion from others around them, including their own families. Children with challenging behavior and mental retardation and/or autism stress the support capacities of families, teachers, and others (Bouma & Schweitzer, 1990; Koegel, Schriebman, Loos, Dirlich-Wilhlem, Dunlap, Robbins, & Plienis, 1992; Quine, 1986; Robbins, Dunlap, & Plienis, 1991; Turnbull & Ruef, 1997) which can influence parents to place their children outside the family home (Blacher, 1994; Bromley & Blacher, 1991). Challenging behavior also affects the educational system and is the primary reason schools exclude students with severe disabilities from general education programs (Horner, Diemer, & Brazeau, 1992; Sprague & Rian, 1993).

When challenging behavior goes unabated, the person with a disability, as well as all involved in providing support, experience a reduced quality of life (Markey, 2000; Ruef, Turnbull, Turnbull, & Poston, 1999). Behavioral science has recognized quality of life issues and left its concentration on solely behavior and that, which precedes and follows it (Alberto & Trountman, 1990). A newer focus, referred to as positive behavioral support (PBS), recognizes the relevance of the individual's choice and comprehensive lifestyle supports. Although PBS has gained momentum in recent years as a favored researcher approach to behavioral interventions, few lifestyle enhancements have resulted as outcomes of studies undertaken (Carr et al., 1999; Turnbull & Turnbull, 2000).

The question then remains: How much information on PBS or on other forms of behavioral support is being effectively communicated and disseminated? Recent research indicates that a gap still exists. For example, one study of 17 families each having a member with moderate to severe mental retardation and challenging behavior reported families as having no systematic way of obtaining useful information to address their child's daily behavioral challenges. In particular, they narrated frustration in accessing relevant information written in non-technical language (Ruef et al., 1999; Turnbull & Ruef, 1996).

In an attempt to bridge the gap between research and knowledge utilization, this study used a participatory action research (PAR) approach. PAR emphasizes useful outcomes and collaboration between researchers and intended beneficiaries. Constituent participation in every research phase increases the probability that problems are not only identified and solved, but also that solutions are useful and used by constituents (Bruyere, 1993; Meyer, Park, Grenot-Scheyer, Schwartz, & Harry, 1998; Whyte, Greenwood, & Lazes, 1991; Markey, 2000; Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998; Turnbull, Friesen, & Ramirez, 1998). Using the PAR approach (i.e., an advisory committee composed of members representing each of the six stakeholder groups provided input at all stages of the research), researchers examined the perspectives of six stakeholder groups (administrators and policy makers, families, friends, individuals with mental retardation and/or autism who display challenging behavior, researchers, and teachers/practitioners). This article, which describes a component of a larger research project, focuses on the following research question asked of all six stakeholder groups:

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 and face-to-face focus groups was the source for data collection. Focus groups were chosen as a method as they: (a) enable participants to identify and describe issues important to them and (b) they create a secure and nonthreatening environment conducive to meaningful interaction, especially important for groups such as

individuals with challenging behavior and cognitive challenges and their family and friends, who historically have had a limited amount of power and influence (Brotherson, 1994; Krueger, 1994; Marshall & Rossman, 1995; Maxwell, 1996; Morgan & Krueger, 1993; Silverman, 1992; Stewart and Shamdasani, 1990).

Participants

The 63 focus group participants were selected using purposive sampling following procedures outlined by Lincoln (1995), Lincoln and Guba (1985), and Patton (1990). Organized to represent the viewpoints of six diverse stakeholder groups, participants were mixed, depending on the stakeholder group, with respect to some or all of the following: (a) family characteristics, (b) gender, (c) age, (d) geography, and (e) link to disability. Additionally, participants were screened by both general and group specific criteria (see Table 1).

The 12 administrators and policy makers chosen from national (4), state (4) or local (4) organizations, were leaders in the area of disability and represented eight states and Washington, DC. The 13 family members chosen represented urban and rural areas in eight states and included individuals defined to be "family" members (see Table 1 for the definition of family). 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. One family member was African American, and one was a native Spanish speaker. These family members' children with mental retardation and/or autism ranged in age from 5 years to 33 years. Of the 11 children, 8 had primary diagnoses of autism, and 3 had diagnoses of mental retardation. Eight were boys, and three were girls.

The 12 friends represented urban and rural areas in six states and ranged in age from 13 years to 45 years. Ten friends were female, and two were male.

The nine individuals with disabilities and/or autism represented urban and rural areas of five states. Five participants were diagnosed as having mental retardation. The remaining four individuals were diagnosed with autism. Although two of these four had difficulties communicating verbally, none had a clear diagnosis of mental retardation. Ranging in age from 24 years to 45 years, six of the nine individuals were men, and three were women. One was African American, and eight were Caucasian.

The seven researchers chosen all had published one or more articles in peer-reviewed journals in the area of challenging behavior and disability. In addition, they could not have been members of the center that was affiliated with this research study. Finally, researcher participants fell into two groups. One group described themselves as advocates for the use of "positive procedures only," while a second group described themselves as "open to the use of aversive procedures under some circumstances."

The 13 teachers and practitioners chosen represented 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 worked across elementary (2), middle (1) and high school (1) levels and had an average of 15 years of experience in teaching students with disabilities and challenging behaviors (range = 3 to 25 years). The seven special education teachers had an average of 12 years of experience (range = 5 to 27 years) and worked with preschool students (1), elementary-age students (2), and with middle, high school, and transition-age students (4). Four special educators worked in special education resource rooms, two worked in inclusive settings (one preschool, one high school), and one worked in a self-contained classroom for students with behavior disorders. The two speech-language pathologists had 6 and 18 years of experience supporting students with challenging behavior ages 3 through 18. They represented suburban and urban geographic areas.

TABLE 1

General Eligibility Criteria and Individual Stakeholder Group Criteria

Term	Description
General eligibility criteria	Any serious episode of the type that requires 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 - hurting oneself by banging, hitting, biting or ingesting foreign, nonedible substances, (b) physical aggressiveness - hurting others by hitting, choking, pulling hair, or biting, (c) property destruction - destroying furniture, clothes or objects.
	Engagement in the types of behaviors described above *or* provision of support to individuals engaged in behaviors similar to these as defined by stakeholder group criteria.
Stakeholder group screening devices	
Administrators and policy makers	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.
Families	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.
Individuals with disabilities	(See Screening Criteria for Challenging Behavior) Be a minimum of 13 years old.
Friends and peers	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).
Researchers	Not be affiliated with the research consortium affiliated with study. Have published one or more peer reviewed articles in the area of challenging behavior.
General and special teachers	Support at least one individual with challenging behavior and cognitive challenges on a weekly basis. "Support" in this context means being responsible for planning and implementing individual instruction or daily living activities for one or more hours a week.

Twelve focus groups (two for each of the 6 stakeholder groups) were conducted. All but the focus groups with individuals with disabilities were conducted by conference call. Focus groups of 3 to 7 persons were conducted, with an average group size of 5.5 persons. This number was consistent with group sizes for telephone focus groups suggested by Krueger (Personal communication, November 21, 1997). In addition, two follow-up individual interviews were conducted with individuals with disabilities. The stakeholder group "individuals with disabilities" contained two subgroups, "individuals with challenging behavior and mental retardation" and "individuals with autism," both involved one face-to-face focus group.

Participants were recruited by telephone or personal contact in a multi-step process described by Patton (1990). Researchers sought nominations of potential participants by contacting over 40 individual researchers, families, and teachers as well as parent and professional groups across the country. A nomination request was also sent to families and professionals on the mailing list of The Family Connection, a nationwide program aimed at providing informational support to families and teachers of individuals with disabilities and challenging behavior.

Once nominees indicated a willingness to participate, researchers contacted them by phone and determined if they met the general requirements and one or more sets of stakeholder group specific participation require- ments (See Table 1). Names of persons indicating willingness to participate in the study and meeting both the general and group specific requirements were placed on a master stakeholder list of names. Researchers purposively selected focus group partici- pants from each of the six master stakeholder lists.

Participants for the group, "individuals with disabilities" were recruited in a different manner. For the first of these groups, comprised of individuals with challenging behavior and mental retardation, researchers established a pool of adults with chal- lenging behavior and mental retardation via an adult service agency in a local community. Researchers recruited members for the second focus group, comprised of persons diagnosed with autism, with the help of The National Committee on Autism. As this focus group was held during The National Committee on Autism's annual conference, this group was composed of both local registrants (from the greater Washington, DC area) as well as registrants traveling to the conference from different urban and suburban areas of the country.

Data Collection

Ninety-minute focus groups conducted over a 5-month period were completed by a team of five researchers. One researcher served as focus group moderator, and the other researcher(s) served in a support role. Moderators varied from stakeholder group to stake- holder group based on experience with a particular stakeholder group. At least one additional researcher was present at each focus group to operate an audiocassette recorder, keep track of time, and take accompanying notes. To provide consistency, the principal researcher moderated or acted as support researcher at every focus group.

The questions contained in the interview guidelines grew directly from the research question and set the agenda or direction for the focus group discussion. In addition, a series of probes or sub-questions were generated to take into account the unique contributions that each stakeholder group could make. The focus group sub-questions also took into account the cognitive abilities of persons with mental retardation and/or autism using methods described by Biklen and Mosely (1988). Although the research question was used as a general guide, participants were encouraged to address issues and concerns most important to them. Our goal was for participants to discuss their priority interests regarding information dissemination and utilization in regards to challenging behavior rather than to simply follow our questioning protocol in a lockstep manner. As focus groups were completed, the research team continually met to discuss emerging themes, which were later used, when appropriate, as general probes. All focus groups were tape recorded and transcribed.

Data Analysis

Researchers used a transcript-based, constant compare- ative method of analysis for this study (Glaser & Strauss, 1967; Krueger, 1994; Miles & Huberman, 1994) reviewing all field notes, summaries of debriefing sessions held after each focus group, 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 purposely systematic and involved established techniques including: (a) organization and reduction of raw data, (b) generation of categories and codes, and

(c) interpretation of patterns and themes (Knodel, 1993; Miles & Huberman, 1994; Merriam, 1998; Seidman, 1991). Data analysis was facilitated by the use of the computer software program, Ethnograph (Seidel, Friese, & Leonard, 1995).

Researchers conducted a formative confirmatory analysis by constructing and organizing a labeled paper trail of relevant materials including notated transcripts, a decision diary, and final results as a method for ensuring soundness. An outside researcher with recent publications using qualitative inquiry published in peer-review journals reviewed the paper trail and confirmed the overall soundness of the research process.

Results

Findings from this study will be discussed according to the following themes: (a) information sources, (b) information strategies, (c) information content, (d) information formats, and (e) information audiences.

Information Sources

Either directly or indirectly, all stakeholder groups commented on information sources. Although individuals with disabilities did not comment directly on important information sources, it appeared they received information from those they knew or trusted. Participants who no longer lived at home talked a lot about various persons who provided them with support as helping them learn various social, vocational and recreational skills. Participants who still lived at home suggested their parents as information sources.

All other stakeholder groups commented directly on informational sources they had already found credible and useful or considered potentially credible and useful. Administrators and policy makers and researchers suggested professional organizations as a source of information. One national teacher union representative, for example, described a summer trainer-of-trainers' seminar available to members:

It's [teacher union sponsored seminar] for our members, and they are nominated by their local presidents to come and work with us for a week in the summer [on behavioral support strategies]. Then they are expected to go back and disseminate it [what they learned] among their peers when they go back to the classrooms.

Administrators and policy makers also viewed institutions of higher education as potentially credible

and useful sources of information. One participant described the value of professors maintaining closer ties with practitioners:

I would really love to see some of our college professors get out in the field more than they are able to do or they want to do, I'm not sure which. I'd like for them to take their curriculum out there and look and see if they can find anything. . .and there we may find some room to do some changes in some curriculum.

Families, friends, and teachers all ranked information from like stakeholders as most valuable. Teachers, for example, liked idea sharing sessions where they could get together with other teachers on a regular basis to share ideas, problems, and solutions. Characteristic of the desire of teachers, families, and friends was the following teacher response:

I took a poll of some of my colleagues in my department before we talked tonight. Almost 100% said, "Teacher to teacher."

In addition, friends described appreciation of family, other friends, or support persons who answered questions or provided support when situations occurred that left the friends unsure:

I had many people who were also involved at the same time when I was first 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 him was able to model behavior for me or to guide me in a certain way as to what I should do and that sort of thing. It was really quite a bit easier for me, and I really consider myself lucky. . .

In validating their preference to receive information from like stakeholders, families and teachers described the value they gleaned from focus group participation:

Family group participant 1: I would really like to talk with the parents of B., because it seems like they have experienced something--my child has also been abused, and I would like to talk with them a little bit more, maybe later off line or whatever, if possible.
Family group participant 2: I think a lot can come out of this [focus group]. We can take a lot of our information that we get from each other, not only for ourselves, and share it with our local parents group.
Teacher group participant: Well, I think it's exciting to hear what's going on in other places, and I'm anxious to share this with my colleagues. And I

think that if something like this [telephone focus group] could be set up on a regular basis, it would help so many different people.

Information Strategies

Administrators and policy makers, friends, researchers, and teachers suggested information strategies. Administrators and policy makers suggested involving stakeholders:

I think if I were going to figure out how to do that [i.e., effectively disseminate information], I would ask people like superintendents and union presidents and maybe school board members and city council people, how does that information get distributed around so that it gets used effectively. You know, what works best.

Friends and teachers stressed the importance of disseminating information person-to-person as an information strategy as well as a source. They also believed public service announcements would be effective:

We would like to see public service announcements such as they show for AIDS awareness, and have one on autism.

Researchers, who described themselves as favoring positive approaches to managing behavior, also mentioned working with the media to popularize positive approaches to behavioral support. Participants suggested approaching television programmers with ideas on melding behavior support into programming and being ready to take advantage of media opportunities, such as the media request on autism coinciding with the movie Rainman but described the difficulties in marketing the "positive only" message:

I think it is very hard to compete with the people who are advertising their aversive procedures, because what we're suggesting is a process, and it's not the same for every kid. And so it doesn't package into a sound-byte as easily as an electric shock or noxious spray or whatever.

Researchers noted their own inexperience in dissemination. To remedy this, they suggested working with university news services, applying for academic communication fellowships, collaborating with professional writers, and applying for and receiving information dissemination grants.

Information Content

All groups commented on information content. Administrators and policy makers and individuals with disabilities contributed less to this theme while parents, friends, researchers and teachers contributed more. Rather than enumerating specific types of information, administrators and policy makers stressed the need for better preservice teacher preparation in the area of positive behavioral support. Individuals with disabilities were nearly silent on this theme with one participant contributing the need for researchers to study how persons with autism could be more flexible.

Parents and friends both distinguished between information available and information desired.

Information available. Parents described information on diets, ecolalia, facilitated communication, functional analysis, and medications as useful. To this list, friends added relationship profiles (e.g., information on preferred activities, places, people, routines) and how to construct crisis plans as useful types of information. In bridging these two types of informational needs, one participant suggested a creative use of business cards to disseminate useful information:

One thing that's helped our program with our friend is we carry business cards that have been donated by a local printing agency. They have likes, dislikes and overall characteristics of the child, so if I'm in my crisis mode with my friend, I can pass out a business card to those people who choose to stand around and stare. We want to promote education vs. ignorance. So we always leave them with a card that promotes awareness of autism or awareness of the disability of the person I might be with.

Information desired. Parents described information at a more intense training level as missing in many areas. For example, one participant described that while many persons with disabilities have personal futures plans, information on how to implement the plans was lacking:

Here [names state] they recommend personal futures planning on the form that the parents, and the students, and the teachers fill out during the transition conference. However, nobody knows how to do it. . . Nobody knows how to really get the community involved.

Friends, on the other hand, stressed the need for more generic information on the positive contributions made by persons with disabilities:

One thing I hear a lot, people are like, "You're so nice to work with these people." And I think the community needs to be more aware that I learn just as much from them, and I have just as much fun with them, and they're just as normal as we are. . .it shouldn't be abnormal to work with somebody with a disability, to be with somebody with a disability.

Researchers' comments on information content differed by their orientation to the use of positive procedures.

Group adhering to positive procedures only. Those advocating a positives-only approach described the importance of limiting information to that which described antecedent-oriented, proactive approaches that involved skill building and environmental manipulation. Those advocating a positives-only approach also stressed caution in dissemination:

When we talk about dissemination, I'm still not very confident personally when I go out to a setting. I can do some assessment, I can do some analysis. I don't feel though, that I can make promises about solving problems. And I find that an important thing to acknowledge early on that we're still in our infancy in terms of what we know, and when we disseminate, I wouldn't want people to have great expectations that were so great that they would then throw the baby out with the bath water because we've represented ourselves in too grandiose a fashion.

Finally, one participant described informational content he wished would be developed into a product. In describing the difficulties of providing skill-level training in behavior support strategies, he wished for an assessment that would enable consultants to measure the capability of an environment to meet the needs of an individual with challenging behavior. He also wished for a curriculum that would provide activities at different levels of sophistication that could be matched to an environment's capability:

So positive behavior supports, when we're starting to really get people to utilize them, are an evolving process that don't often have clear single subject designs to accompany them. . .they tend to be much more muddied by the limited capabilities of real life environments. . .if there was some attention to how do you assess the capability of an environment, and how do you match that to the person's individual needs, and provide an incremental plan that [would enable] the environment to evolve… I'd love to see something like that.

Group open to the use of aversives. This group stressed the importance of making clear which philosophical approach to behavior management a particular informational product supported or represented. This group also described how limiting dissemination to proactive, skill-building types of behavior strategies would be misrepresentative of the field:

I think you'll find a number of studies in the literature where educational things have not worked. Therefore, the reason why the study was done was to eliminate behavior that interfered with the educational process. And if you exclude those, what you're saying is we're not going to look at any study, because it's published with the emphasis of eliminating this [behavior] rather than on education… If you eliminate that, you're really not representing the field at all because positive interventions could be used to build those skills once an intervention was used to eliminate something that prevented education from occurring.

Teachers mentioned the value of research-based awareness and skill-level information on behavioral support. Their requests of skill-level information were specific and prescriptive in nature:

Participant One: Maybe a checklist of strategies that work… Ideas; try this, try this, try this… lots of examples… a how-to manual.
Participant Two: Listing specific behaviors… How we should react, to prioritize, what we should do first, what we should do second, that kind of thing.

Information Formats

All groups commented on information formats. Format themes arising across groups were (a) written, (b) interactive, and (c) multi-media.
Written formats. Friends and families stressed that written information be brief and readable. One participant in the friend group commented that, "…things that are really helpful aren't in articles." Only one of 12 teachers preferred written information [as compared with other formats], and all teachers agreed with parents that written material should be limited to one or two pages:

I asked some of my colleagues today because I know this question [was going to be discussed], and they said as long as it was very short and to the point, then they would have time to do [read] it.

Researchers, too, described the relative ineffectiveness of professionally-written journal articles and manuals in reaching a broad audience. One participant described inserting an offer to collect $10.00 in the middle of a manual she had written in order to purposefully determine if her manual was being read. Only one person from a large staff appeared to collect the $10.00 reward:

I think the sad part is that what most of us do is write articles, books, and manuals that nobody ever reads, and we continue to do this. . .I mean there are academic reasons why we persist in doing this, but clearly. . .if the goal is to get information really out, clearly everybody is right in that information won't do any good unless you have good systems of support in place, which is the hard part.

Rather than relying on journal articles that researchers described as "technical" and "difficult to follow," researchers in both focus groups instead suggested a book written in a popular style by a professional writer in collaboration with an expert in the area of behavioral support. They cited the popularity and resulting impact of the book, *Let Me Hear Your Voice,* by Catherine Maurice has had on the field of autism and suggested something similar on behavioral support as a good idea. Researchers also mentioned "how-to" booklets and simplified reviews and reports in local newspapers as effective ways to reach parents and others outside academia.

Interactive formats. As mentioned earlier, families, friends, individuals with disabilities and teachers all mentioned receiving information from like stake-holders. They also described a preference for receiving information from those other than like stakeholders in interactive formats. For example, families, friends, individuals with disabilities, teachers, and researchers all mentioned the importance of not only receiving information, but also of hands-on assistance in utilizing it:

Moderator: Did she [the parent/professional giving information] tell you about functional analysis, or did she give you anything to read, or did she help you with it?
Family Participant: She did a workshop… I attended the workshop and then she helped me put the plan together.

Individuals with disabilities described learning via interactive role-playing, modeling and practice as a way that complemented their learning styles:

Moderator: How did they [support providers] teach you?
Participant: Well, just like learning how to cast [fishing]. It took some teachin', but I worked on it. F. [staff person] taught me how to do a lot of stuff. How to get up in the mornin', take a shower, brush my teeth, unlock the door, how to work on cars…
Moderator: Did he tell you or show you?
Participant: No, he showed me.
Moderator: Is that the way you like to learn?
Participant: I like to be able to practice and have someone show me.

Lastly, teachers preferred inservice trainings that incorporated the sharing of success stories.

Multi-media formats. Administrators, families, friends, researchers, and teachers all mentioned various forms of multi-media such as video-conferencing, the internet, (e.g., the autism listserv) and videotapes. Friends, researchers, and teachers all commented on the effectiveness of videotapes. In commenting on multi-media formats such as videos, friends and teachers described the vividness of this format. They liked the use of color and their ability to actually view support providers successfully supporting individuals with challenging behavior. One teacher comment summarizes the remarks made:

I agree that a videotape is something that you can view at your own leisure, you can see it again and again. We agree that having a videotape dealing with some of these things where you can see it, see how it works, and you can… bounce it off each other, send it to parents, send it to a group of people, you know, where they can all see it at their leisure, works for us.

Information Audiences

Administrators and policy makers, families, researchers, and teachers commented on information audiences. Comments reflected informational needs that stakeholder groups saw themselves as having as well as needs they saw for others. Participants recommended that the type of information be matched both by purpose and by audience. For example, participants recommended targeting professionals with more detailed skill-level information, while they recommended targeting the general public with less detailed, awareness level information. Viewed as a continuum, these audiences included: (a) the general public, (b) administrators and policy makers, (c) families, (d) teachers.

The general public. By including the general public that might encounter a person with challenging behavior in the community in their comments, participants seemed to include everyone. Some of the types of people described were Boy Scout leaders, high school and college students, business owners, legislators, physicians, teachers, parents, and behavioral consultants. In presenting awareness-level information to the general public, participants saw an opportunity to create more of a demand for information and for an opportunity to influence people's thinking about behavior on a more preventive level.

Administrators and policy makers. Although administrators and policy makers did not indicate that they themselves needed or desired information, both parents and teachers suggested targeting administrators and policy makers as pivotal audiences:

But I think when this [the products that result from the study] comes out, this will be a wonderful way to perhaps maybe go to some of my 'higher ups' in my administration, and say, "Please take a look at this," and "How can we disseminate this information to other people throughout the district?" And I think that's the biggest challenge.

Families. Although families were suggested as information audiences by administrators and policy makers, researchers and teachers, families suggested that the primary targets for information dissemination should be professionals who work with their children. Families also described information as being hard to find. Characteristic of comments was one made by a parent who accidentally found helpful information on the Feingold diet in the newspaper:

It just seems to me there's no place to go. All these agencies and all these places, you have to find them yourself, or find them through word of mouth, or through the Internet. You know, it's a search where, you know, I could see where somebody who needs help, they have a handicapped child [and] they're completely lost.

In addition, one parent criticized schools and teachers for displaying elitist attitudes regarding information sharing. In describing the benefits that can accrue when parents receive information from professionals, this participant suggested that some professionals may intentionally withhold information:

There's a lot of things that I've learned over the past three years, in terms of therapy for B. [daughter] that we can do to help her. Hands-on stuff that parents can do – I didn't know until the last three years that

have helped calm her down. Like the occupational therapy exercises that keep her calm. I think often times the professional community keeps an elitist attitude and holds these things to their chest rather than sharing them with the parent.

Teachers. Although the amount of training required both at the pre- and inservice levels differed from state to state, and from local district to local district, administrators and policy makers, families, researchers and teachers described teachers as having an overall lack of training in positive behavioral support. Parents of students with autism were particularly critical of how little educators know about autism:

I'm just thoroughly and continually amazed and appalled at the lack of information that professionals have on autism… Autism is a separate category as a disabling condition in [names particular state], yet… there's no specific training on autism for the psychologists that are rating the assessments and providing the recommendations that often drive the IEP instruction. I find this absolutely amazing and appalling. There's no way for a parent to get good solid information when she's gone to the first case conference for the three year-old-child. She's sitting there with a professional who doesn't know "diddly." So how in the world can they serve as mentors and guides for this young parent who is asking for help … for the real basic stuff?… They [parents] are left high and dry by the professionals.

Discussion

The discussion section provides a description of the limitations of this study as well as a discussion of three key themes and recommendations for future practice.

Study Limitations

Limitations of this study include: (a) cautions about making generalizations based on participant comments, and (b) possible sources of researcher bias. The purpose of this study was not to make sweeping statements about positive behavioral support information or the perceptions of stakeholder groups. The primary purpose, rather, was to give voice to 63 participants representing six stakeholder groups in an attempt to better understand their experiences and perceptions of informational products that could be helpful in increasing quality of life while reducing or eliminating behavioral challenges in people with disabilities. Although care was taken in selecting a

nationwide group of participants from over 40 sources who met both general and stakeholder group specific screening criteria, these participants may, in fact, not have accurately represented their respective stakeholder groups. This may have resulted in important themes not emerging. Lastly, although care was taken to ensure the trustworthiness of this study (i.e., 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 may have influenced the identified findings. For example, all researchers involved in the study were family members of persons with disabilities. Their orientation as family members may have influenced the emergent themes.

Key Themes and Recommendations

In converging divergent stakeholder perspectives on useful information, the following four themes emerged as worthy of further comment: (a) establishment of trust relationships as a prerequisite to research and information dissemination and utilization, (b) provision of technical assistance in the use of the information provided, (c) provision of easy access to relevant research-based information, (d) provision of tiered levels of information in a variety of formats, and (e) inconsistence in how stakeholder groups perceived their own needs versus the needs of other groups.

Establishment of trust relationships. Although all groups agreed on the importance of research-based information, stakeholder groups involved in providing direct support (families, friends, and teachers) called for an increase in research relevant to their needs and for an expansion of product formats beyond journal articles and research reports. Busy providing direct support, families, friends, and teachers described having no time or interest in accessing, reading, and/or deciphering how such articles and reports might be meaningful to them. Instead, they stressed the importance of receiving information from like stakeholders they knew and trusted. Trust relationships with these friends or colleagues, people who had already "walked a mile in their busy shoes," were easier to establish and occurred, even as we listened, during the course of 90 minute telephone focus groups.

In contrast to the importance placed on trust relationships by parents, friends, and teachers, administrators and policy makers and researchers left these subjects untouched. While researchers did express an awareness of the fact that their work was not being sufficiently utilized and called for wider dissemination in a broader variety of formats, they seemed unaware that "one of the most effective ways to increase utilization (the goal of all dissemination)-and to improve the quality of research-is to involve potential users in planning and implementation of the research design itself" (National Center for the Dissemination of Disability Research, 1996, p.38). Indeed, establishing participatory relationships may be a prerequisite to effective information dissemination and utilization.

One recommendation, then, is to incorporate the participatory action research model into behavioral support research design to create useful, useable information (Santelli et al., 1998; Turnbull et al., 1998). By meaningfully including stakeholders from the inception of a research study, the distance between researcher and stakeholders is lessened and trust, a crucial element in knowledge utilization, is increased. Describing her satisfaction with the PAR approach, one parent leader of a community parent resource center for culturally diverse families of children with disabilities described the "immediate and direct benefits for all who were involved" and that the concerns of parents [involved in the study] were "… heard by researchers for the first time" (Markey, 2000, p.189).

Provision of technical assistance in the use of the information provided. The gap between research and practice was nowhere more evident than in comments made about supporting support persons with technical assistance. Although the need to provide technical assistance was a theme that echoed strongly through 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 theme. The comments that administrators and policy makers did offer were in relation to teachers only. These comments addressed mainly the question of resources (i.e., the time and money needed to provide technical assistance). Only passing mention was made of offering technical assistance to families, and no mention was made of offering it friends.

Given the research on the critical role families play in supporting individuals with disabilities (Turnbull & Turnbull, 1997) and importance of on-going technical assistance (Bruner, 1993; Gersten et al., 1995; Gersten et al., 1997; Newman & Vash, 1994) the question remains: Why such a limited discussion of this type of informational support by those in a position to make positive changes? This lack of discussion is particularly ironic when one considers the success experienced by friends, the only group that boasted being supported by technical assistance in an on-going manner.

Additional research is needed to identify the factors that allowed those receiving on-going technical assistance to successfully provide on-going support to individuals with challenging behavior. Programs such

as Kansas Department of Education's Field-Based Consultants Network (Bashinski et al., 1999), for example, should be further explored as cost-effective models to provide on-going technical assistance to stakeholders (e.g., teachers) by like stakeholders.

Ease of access to relevant researched-based information. Although all groups agreed on the importance of disseminating research-based information to a wide variety of audiences in a variety of formats, they all also agreed that direct provider groups (i.e., families, friends, and teachers) currently do not have adequate access to the information they need. Knowledge about behavioral support may be most wanted and best used when a problem occurs and a parent, teacher, or other support provider is at his or her "wits end" (Savolainen, 1995). While presenting information only when it is propitious is a justifiable concern of teacher educators and others involved in professional preparation, strides could and should be taken in improving information accessibility. Information accessibility incorporates more than geographical location; it also encompasses low or no financial cost, ease of comprehension, and redundancy. Information redundancy increases information continuity, communication, identity and social resonance (Katz & Rothenberg, 1996; Klapp, 1986). Repeated information funneled through multiple channels leads to message absorption (Katz & Rothenberg; Lieb-Brilhard, 1989). Researchers and other groups that disseminate information should strive for an appropriate level of redundancy, knowing that too little will increase the chance of the message being lost amidst the larger information environment and that too much increases the chance that ". . .so much time will be spent accessing and absorbing the message that it will detract from the energy and time available to implement the action recommended in the message" (Katz & Rothenburg, p.3).

Employ tiered levels of information in a variety of formats. All stakeholder groups echoed the need to provide a variety of information levels from awareness to in-depth and skilled levels and to match informational formats with audience preferences. While it is true that researchers do need to document their work in statistical compilations, technical reports, monographs, journal articles and other publications, they could also provide awareness-level information summarizing versions of their studies, ideally through the popular media. Additionally, they might produce one-page (a preferred length of teachers, friends, and families) fact sheets that offer the reader general information and provide references for more in-depth publications.

In addition, people seem more inclined to seek additional information on a topic after an initial "lively medium." If the adage, "after I saw the movie, I read the book," can be generalized to the reading of non-fiction, behavioral support literature, more vivid forms of media should be considered in introducing audiences to behavioral support strategies. Participants mentioned collaborating with writers of popular fiction, television producers and using World Wide Web sites, all of which offer potential for presenting concepts and ideas in a lively manner using color, graphics, animation, and interactivity.

To provide stakeholders with more advanced or skill level information, participants of this study suggested that some form of mentoring is probably necessary. Participants further suggested that mentoring is most effective when provided by similar, trusted people, people who have "walked a mile" in their shoes.

Inconsistency of stakeholder group perceptions of their own needs versus the needs of other groups. All stakeholder groups but administrators and policy makers described perceptions of both their own informational needs and the informational needs of other groups. Parent participants, for example, in describing their own informational needs, mentioned wanting information on how to implement personal futures plans. In describing their perceptions of teacher informational needs, parents mentioned more training in the area of autism. Similarly participants in the friend, individual with disabilities, researcher, and teacher stakeholder groups all described perceived informational needs of their own as well as those for other stakeholder groups. In contrast, however, administrator and policy maker participants limited their remarks on information and dissemination to teachers. They did not address the question of what information and dissemination would be useful to themselves or to other constituency groups in supporting persons with disabilities and challenging behavior. As administrators and policy makers play key leadership roles in supporting individuals with disabilities and challenging behavior, additional research needs to define more clearly the informational needs of this group regarding positive behavioral support.

Conclusion

If we agree that the goal of conducting research on behavioral challenges in the field of special education is to improve behavioral outcomes for individuals with a disability, then it follows that those conducting research studies need to carefully plan for dissemination/utilization from the inception of their research projects. Researchers need to allocate time and resources to dissemination/utilization activities. If

we further agree that the underlying assumption on the part of all stakeholder groups is to provide comprehensive, preference-based support for persons with mental retardation and/or autism, then all stakeholder groups must begin to establish trusting, collaborative relationships, and the voices of families, friends, teachers, administrators, policy makers, and others who provide support must be clearly heard.

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