

# *Family Perspectives on Inclusive Lifestyle Issues for People with Problem Behavior*

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**ABSTRACT:** *Interviews were conducted with 17 families of children, youth, and adults with problem behavior (e.g., aggression toward others, property destruction, self-injurious behavior, and pica). From a larger study addressing many questions, the data reported in this article focus on inclusive lifestyle issues that are important to families. Results are organized into categories that emerged from the qualitative analysis, including family life, friendship issues, school issues, community inclusion, and supported living/supported employment. Themes suggest extremely scant and tenuous inclusive lifestyle supports for these people and their families. Key recommendations focus on expanded family support and priority topics for research and training*

Positive behavioral support is characterized by value-based principles consistent with the developmental disability policy of independence, productivity, and inclusion. Merging the behavioral research body of knowledge with current work in augmentative communication, self-determination, friendship facilitation, school inclusion, supported employment, and supported living, positive behavioral support principles, as identified in Figure 1, offer a wholistic and multifaceted approach to providing personalized supports and services. Increasingly, research and demonstration models characterized by positive behavioral support have been described as emphasizing inclusive lifestyle change (Carr et al., 1994; Foster-Johnson, Ferro, & Dunlap, 1994; Koegel, Koegel, & Dunlap, 1996; Lucyshyn, Olson, & Horner, 1995).

Horner and his colleagues described the meaning of a lifestyle focus as follows:

The positive/nonaversive approach focuses on the lifestyle of the individual, in addition to the frequency, duration, and intensity of the challenging behaviors (Horner, Dunlap, & Koegel, 1988). Behavioral support should result in durable, generalized changes in the way an individual behaves, and these changes should affect individual's access to community settings, social contacts, and to a greater array of preferred events. Among the most important issues for a technology of behavioral support is recognition that the standards for assessing "success" are changing. (Horner et al., 1990, p. 127)

## FIGURE 1

### *Principles of Positive Behavior Support*

1. Focus on the person's entire lifestyle and emphasize procedures for helping to build relationships and for including the person in preferred activities, places, and events.
2. Use functional assessment to pinpoint the reasons for the problem behavior and to ensure that the intervention program responds to those reasons.
3. Use the multiple interventions and recognize that a single one is rarely adequate.
4. Build the plan around many different events such as exercise, noise levels, sleeping patterns, and eating schedules.
5. Change the events that seem to elicit problem behavior.
6. Teach adaptive behavior such as communication skills so the student can express frustrations rather than act out.
7. Help the student develop a wider range of interests so that effective reinforcing events can be arranged.
8. Minimize punishers.
9. Put emergency procedures into place so that families and educators know exactly how to respond in crisis situations.
10. Choose behavioral interventions that respond precisely to problems and that are the least intrusive possible.
11. Make sure that all behavioral interventions maintain and support the person's dignity.
12. Do not use procedures that typical members of the community would find offensive.

*Note:* From "Toward a technology of 'nonaversive' behavioral support," by R. H. Horner, G. Dunlap, R. L. Koegel, E. G. Cars, W. Sailor, J. Anderson, R. W. Albin & R. E. O'Neill, 1990. *Journal of the Association for Persons with Severe Handicaps*, 15(3), 125-132. Copyright 1990 by the Association for Persons with Severe Handicaps. Adapted with permission.

From this definition, indicators of lifestyle quality appear to be access to community settings, social contacts, and a broad range of preferred events.

If Horner et al. (1990) are correct in stating that the "standards for assessing 'success' are changing" (p. 127), educators and researchers have not yet provided a definitive determination of exactly what the new standards are for evaluating lifestyle-change efficacy.

We define an *inclusive lifestyle* as pervasive participation in family, friendships, school, work, and community life consistent with one's preferences and characterized by personalized supports and reciprocal relationships. Despite the growing body of research and policy supporting inclusion of students with disabilities in general education settings (Hasazi, Johnston, Liggett, & Schattman, 1994; Osborne & Dimatta, 1994), ample evidence shows that families, schools, and communities are experiencing significant barriers in accomplishing successful inclusion of students

with problem behavior (Horner, Diemer, & Brazeau, 1992; Stanford Research Institute, 1990; White, Lakin, Bruininks, & Li, 1991).

Consistent with the participatory action research model in which potential research beneficiaries collaborate to define the research agenda from the outset (Hoshmand & Polkinghorne, 1992; Lather, 1986; Turnbull, A. P., 1994; Whyte, Greenwood, & Lazes, 1991), we undertook this exploratory study to provide input to researchers on family priorities related to inclusive lifestyle issues so that researchers can take these priorities into account when planning and implementing research. From the larger database that was gathered (Turnbull, A. P., & Ruef, in press), this article's primary research question is: What are family perspectives on inclusive lifestyle issues for people with problem behavior?

## METHOD

We used telephone interviews for data collection. The in-depth interviews enabled families to de-

fine the field of inquiry by raising topics of interest to them (Ferguson, Ferguson, & Taylor, 1992; Stainback & Stainback, 1989).

### *Participants*

Using purposive sampling, we selected the family participants. We sought nominations of families from many sources, including family organizations (e.g., Parent Training and Information Centers, statewide and local Parent-co-Parent programs), researchers with a long history of conducting positive behavioral support research, and professionals who provide services to children and adults with problem behavior. Although the term *problem behavior* can be defined broadly, we sought participants who had a family member who met each of the following three characteristics:

- Mental retardation.
- A history of having had at least one incident of aggression toward others, property destruction, self-injurious behavior, or pica during the past 4 years.
- At least one 2-week period within the past 4 years in which there were five or more episodes of one of the behaviors described in the previous item.

In addition to these characteristics of problem behavior, we sought nominations of families representing a broad spectrum of socioeconomic circumstances, age of the target individual, ideological orientation toward inclusion, severity of problem behavior, and past and current extent of family challenge posed by the problem behavior.

Fourteen of the 17 families interviewed reported that the individual with problem behavior met the problem-behavior criteria. We included three additional families who had not experienced at least one 2-week period within the past 4 years in which there were five or more episodes of these behaviors, because of the extensive positive behavioral support that these families provided. Approximately one third of the individuals were at each of the three levels of mild, moderate, and severe mental retardation. (One family indicate that their son had not been tested, but he likely had mild mental retardation; and another family questioned the established diagnosis of mental retardation for their son, since he had recently been

experiencing success with facilitated communication.)

Table I provides demographic information on the families of the people with problem behavior. As noted, 13 families were Euro-American, and 4 were Latino. For two of the Families, we spoke with more than one family member. In one of these situations, we interviewed the father, mother, and brother. In the second situation, we interviewed the mother and a roommate/close friend (who is regarded as a family member) of the adult with problem behavior. In 3 of the families, all members had less than a high school diploma; 5 of the families had one or more members who had completed graduate school. Approximately half the families were from suburban communities, and the other half equally divided between large cities and small town/rural areas.

Of the 17 people with problem behavior, ages ranged from 4 to 35. One child was in preschool, eight in elementary school, and four in secondary school. Four people were receiving adult services. Of the students under the age of 22, 12 were living at home, and 1 was attending a special school out of state. Of the four adults, one was living at home, and three were in a group home or in a supported living situation.

### *Data Collection and Analysis*

One of three interviewers conducted telephone interviews over a period of approximately 5 months, and two interviewers participated in approximately half of the interviews through the use of a speakerphone. The interviews ranged from approximately 30 to 120 min with an average of about 70 min per-interview. All interviews were tape-recorded and transcribed. Using the participant-nomination techniques discussed previously, the nominator contacted the family and asked for informed consent for names to be shared with us. Once consent was obtained and the names were received, one of the interviewers called the family explained the purpose of the study, and asked if family member would be willing to complete screening instrument that included the previously stated problem-behavior criteria. Four nominated families were excluded from the study because they did not meet the study's problem-behavior criteria or because the family was not providing *extensive* positive behavioral support. For the 17 families who met the criteria, a mutually convenient time was scheduled for the interview.

**TABLE I**

*Family Demographic and Individual Placement Information*

<i>Family #</i>	<i>Respondent</i>	<i>Racial/Ethnic Status<sup>a</sup></i>	<i>Marital Status<sup>b</sup></i>	<i>Age of Child</i>	<i>School Placement<sup>c</sup></i>	<i>Employment<sup>d</sup></i>	<i>Home Placement</i>
1	Mother	EA	M	2	SE, V	n/a	Family
2	Mother	EA	M	8	C	n/a	Family
3	Mother	EA	M	10	C	n/a	Family
4	Mother	EA	M	20	V	n/a	Family
5	Mother	EA	M	9	C	n/a	Family
6	Mother R'mate	EA EA	D S	36	n/a	NE	Other
7	Father Mother Brother	EA EA EA	M M S	22	n/a	NE	Family
8	Mother	L	D	7	SE	n/a	Family
9	Mother	L	M	9	SE	n/a	Family
10	Mother	EA	M	8	SE	n/a	Family
11	Mother	EA	M	4	RE	n/a	Family
12	Mother	EA	D	18	SE	n/a	Other
13	Father	EA	M	7	RE	n/a	Family
14	Mother	L	D	10	SE	n/a	Family
15	Mother	EA	W	28	n/a	NE	Other
16	Mother	EA	M	25	n/a	VE	Other
17	Mother	L	M	15	SE	n/a	Family

*Note:* <sup>a</sup> EA = Euro-American, L = Latino; <sup>b</sup> M = Married, D = Divorced, S = Single, W = Widowed; <sup>c</sup> SE - Special Education, V = Community-Based Vocational Education, RE = Regular Education, C = Combined Special and Regular Education, n/a = Not Applicable; <sup>d</sup> NE - Not Employed, VE = Volunteer Employment. n/a - Not Applicable.

The questions for this study were organized around the broad question pertaining to family perspectives on inclusive lifestyle issues. The interviewers developed an initial set of questions and a guide for conducting the interviews. Frequency and duration of topics were indicators of a topic's salience. The three interviewers became sensitized to what was meaningful to the family respondents and pursued issues that were relevant to them. As the interviews were completed, the research team continually met to reflect on the emerging themes and subthemes as raised by the family respondents. These themes and subthemes were used as general probes in future interviews so that the interview guide continued to emerge and was shaped by the previous respondents.

The researchers transcribed the tapes, summarized notes, and identified the key themes and subthemes that emerged in interviews. Using established content data analysis techniques (Krueger, 1988; Morgan, 1988; Skrtic, 1985), the researchers read all transcripts, marking all relevant passages related to the research question and emergent themes and subthemes. These informational units were entered on index cards (coded by respondent and transcript page number) with the full language as it appeared on the transcript. The researchers then sorted the unit cards into categories and subcategories while simultaneously establishing categorization rules as a research team. This analytic-inductive process resulted in the identification of new categories when informational units did not fit previously defined categories (Glaser & Strauss, 1967). This process of starting with individual categorizing and moving to team categorizing occurred after two or three interviews throughout the entire process. As new categories were added at team meetings, the evolving interview guide expanded so that these categories became probes for future interviews.

We used several techniques (Brocherson & Goldstein, 1992; Morgan, 1988) to enhance the rigor of the interview methodology and content analysis, as follows:

1. *Multiple researchers.* At least two researchers participated in at least half of the interviews. During content analysis, three researchers reviewed each

coded statement to discuss categories, agreements, and disagreements.

2. *Member checks.* Information was summarized and presented back to the 17 families who participated in the interviews for verification, along with a 10-question feedback form. The participating families indicated strong endorsement for the interpretation and presentation of the qualitative data. One family indicated that the draft paper was the first thing that she had read that she truly believed "represented the reality of her family life." Several families made suggestions of small changes having to do with spelling and some minor edits of quotes. One mother noted that her views are not representative of her husband's. Several families took this opportunity to provide even more extensive information on their particular perspectives on various issues that were triggered by reading the paper (a sample quote representing additional information is included in the Discussion section).
3. *Stakeholder review.* The draft paper was sent to eight family leaders (parents who actively participate in state and/or national family organizations) who lived in different regions of the country and who represented the racial/ethnic groups of Latino, African American, and EuroAmerican. We asked these stakeholders to identify any issues in the paper that particularly seemed "out of line" to them or to identify any omissions. No corrections were made by the stakeholder group.

## FINDINGS

We organized the findings into categories that emerged from the qualitative data analysis, as follows:

- Family life.
- Friendship issues.
- School issues.
- Community inclusion.
- Supported living and supported employment.

Table 2 summarizes the categories and provides an illustrative quote for each category.

TABLE 2  
*Inclusive Lifestyle Issues: Summary of Themes and Quotes*

<i>Categories</i>	<i>Illustrative Quotes</i>
<i>Family Life</i>	
Siblings	"Of all the difficult parts of this, sibling issues are the most difficult."
Extended Family	"He would just strap his grandson to the toilet until he would go. He would say, 'If I were here, he would be trained!' He doesn't understand that this cannot be forced, and it only makes matters worse."
Home Routines	"If he doesn't know what we are going to do, then he gets real anxious and what he would do in this situation is to start to unload the refrigerator about 90 miles an hour and continually. We just get him out of it, and he is back in it again."
Religious Activities	"I just don't have the energy to look through 30 churches in the area to find the one that is right for Jason and then make all of the efforts to make all the contacts.... It is just one more mountain that you choose to go around instead of to climb."
<i>Friendships</i>	
Current Status	"Danny has no relationships outside his family."
Among Adults	"Aaron pays attention to him, jokes with him, and punches his arm affectionately."
Among Children	"Jesse has no friends at school.... She has only been there 1-1/2 years."
<i>Schools</i>	
Teacher Considerations	"The teacher didn't seem well-trained in dealing with students like Monica."
Administrative Issues	"The principal was trying to decide where to put our son based on things like how many kids are in the class already, what's the ratio of boys to girls, etc.-stuff that totally didn't fit our agenda. We were looking at who is the teacher who is most likely to succeed with him, where there will be a situation that is going to be the least disruptive to him. We had a whole different set of criteria."
Inclusion	"My son sits at the same tables as regular education kids but there is no interaction.... Some of his classes contain joint activities but 'togetherness' is not being facilitated."

TABLE 2 (Continued)

Categories	Illustrative Quotes
<i>Community Participation</i>	"One time I took George to the supermarket, and he kind of jumped up and down and rocked and hummed. He was laughing a lot, and a woman gave me a look. She wouldn't dare say anything, but she gave me a look almost to say, 'Why would you bring a boy like that in here?' She didn't have to say anything. Her look told it all."
<i>Supported Living and Supported Employment</i> <i>Supported Living</i>	"When Rob and I moved in together in this house, I let him have the run of the house because it is his house.... People asked what I will do if I have a problem. I jokingly say half of the people in Boston have problems so we will fit in perfectly. . . . We wrote up house rules ... basically, we don't touch each other's possessions unless we ask first. Second, when we are angry, people must listen to what we have to say." "The staff person from the group home ... criticized my car, because it is only a four-door. They thought I needed a van. I said that I don't need a van, it is only Rob and me.... This is the present and future. The van ride days are over. With Rob moving into his own place, we will save the state \$30,000 a year at a minimum. Rob's situation cost the state easily over \$100,000 a year. Now they pay me \$81.00 per day. They also pay half of Rob's rent, and then I pay half."
<i>Supported Employment</i>	"We have gone there [day program] three to four times, and every time he is just sitting down and not doing anything. He is just playing with blocks."

*Inclusive Lifestyle Issues Associated with Family Life*

Family considerations related to inclusive lifestyle issues focused primarily on relationships with siblings, relationships with extended family, home routines, and participation in religious activities.

*Relationships with Siblings.* Of all the family relationships, there were significantly more comments on siblings. The major types of challenges were reported to be lack of a bond or close connection between the person with the problem behavior and his or her sibling(s), feelings of

resentment about not having a "normal" brother or sister, frustration about having property destroyed, embarrassment about problem behavior around friends or in public, and resentment about the amount of time and attention that the sibling with problem behavior requires. Parents identified far fewer sibling benefits than problems. The benefits *they* mentioned included learning unconditional love, problem-solving skills, and a sense of responsibility.

*Extended Family Relationships.* Approximately half the families commented on relationships with extended families. The majority of

those expressed that grandparents, aunts, uncles, and cousins had a hard time establishing a comfortable and connected relationship with the person with problem behavior. They interacted with the parents and the individual in a way that created resentment and tension. The consistent theme among these families was that extended family members often implied that the child's behavior problems resulted from poor parental discipline.

*Home Routines.* The most frequent home-routine problem mentioned by the majority of families was their child's difficulty being productively involved in home activities. These problems related to the incessant need of some of these children for parental attention and supervision. Parents need breaks and chances to relax, but they reported the chronicity of being "on duty." Families particularly described mealtime, sleeping through the night, weekends, and vacations as particularly challenging and disruptive due to the problem behavior.

A frequent need mentioned by families was the difficulty of finding people with the attitudes and skills to be competent care providers. One parent told of the problems of having a care provider with whom her child did not have a secure relationship: "One sitter had to feed my son Oreos all night or she would get pinched and bitten. She sent her friends to the store and got two boxes of Oreos and fed him Oreos all night long." Parents emphasized the need for information for care providers to prepare them for their roles.

*Participation in Religious Activities.* Over half of the families expressed disappointment and frustration that it was impossible for them to participate in their preferred religious activities as a family unit. For many families, being excluded from a religious community creates family divisiveness, such as for one of the families who indicated that, when one of her children had his bar mitzvah, his brother with problem behavior was not able to be included. She indicated that religious participation would take a "brain transplant for the rabbi."

Reasons stated for exclusion from religious communities included the attitudes and competencies of religious staff, the formal and structured nature of the services, lack of training and support to members, difficulty in obtaining age-appropriate

groupings, and added stress on the parents when they worry that their son or daughter will disrupt others. Although many parents indicated that this area was important to them, several expressed that they did not have time and energy to address it.

#### *Inclusive Lifestyle Issues Associated with Friendships*

We analyzed the friendship data into the three categories: current status of friendships, friendships among adults, and friendships among children.

*Current Status of Friendships.* Over two thirds of the families described the *absence* of even one friendship for their children with problem behavior. Consistently, families expressed some degree of disappointment and even resignation about the children's lack of friends. A parent of a young adult warned: "The older, you are and the longer you wait, the more difficult it becomes." Her strong admonition was to focus on friendships at a young age. The clear consensus among parents appeared to be that they accepted the lack of friendships as almost an inevitability. Only one parent mentioned a vision for friendship: "My dream is that the phone will ring, and someone will invite her to play."

Two parents mentioned intense fear about sexual exploitation. They worried that their son or daughter would be the target of an aggressive encounter. No parent mentioned the vision that their son or daughter might have a mutually gratifying sexual or physically affectionate relationship.

In six instances, families described that friendship had occurred. Four were adults over 18, and two involved school-aged students.

*Friendships Among Adults.* Four 'of the' six people 18 years old had at least one friendship. Parents described the friends as being solicitous; empathetic; and able to laugh, do crazy things, and bring out the very best in others. For one individual, friendships had been facilitated at high school and by a disability advocacy organization. The parent stated that one of the friends started as a volunteer. In the other three instances, friendships were with a current or former staff person.

Each of these relationships started when the staff member provided services to the individual with problem behavior

In all situations, families described a special "connection" that had been made. All staff persons initiated significant companionship outside of work time.

*Friendships Among Children.* Parents mentioned three different methods as potential strategies for providing a context for friendships to occur. These included having the child participate in inclusive settings so that he or she had an opportunity to have social interaction with peers, paying a companion to spend time with the child, and providing information and skills to peers in knowing how to interact. In terms of paying companions, one family paid a "travel" companion to walk home from school with their son. Just as in the case of adult relationships that started with paid staff persons and evolve into a "connection," this same sort of outcome might occur with a paid travel companion.

Some parents indicated that they had asked the teacher to give them a list of "possible friends" so that they might make contacts out of school. One family expressed difficulty in knowing how to initiate contact, and another family indicated that they cried to meet the parents of these youngsters to see if it might be possible to get together as a family. They indicated that this strategy had not been particularly successful. One parent mentioned that neighborhood children needed to know how to "reach" her son.

### *Inclusive Lifestyle Issues Associated with Schools*

The school issues addressed by the families include teacher considerations, administrative issues, and inclusion.

*Teacher Considerations.* Whether children were placed in special or general education classes, families believed that many teachers lacked training in providing appropriate instruction and behavioral supports. Three parents particularly addressed the use of aversive treatment. One parent stated that teachers were trained in aversive behavior management during her son's middle school years, and teachers were instructed to send children to a locked ticket booth when they got upset. Unable to change the situation, the parents' last resort had been to keep her son out of school for the entire year when no teachers were properly trained to teach him.

The majority of families expressed concern and frustration over the following characteristics of the teachers with whom they had dealt: unwilling to change, giving in to students as a way of dealing with problem behavior, becoming defensive when suggestions are made, requiring that parents make an appointment before they come to see the teacher or observe the class (the parents thought that the teacher was "hiding something"), never giving concrete answers, giving up completely on the students, and being intimidated by students with problem behavior.

Three of the 13 parents expressed positive perspectives about the teachers instructing their child. The following characteristics of teachers were particularly welcomed by these parents: being open to change; having energy, enthusiasm, and a positive temperament; having a sense of humor that helped the teacher cope with the problem behavior; getting to know students for whom they really were; trying hard to teach; and taking a personal interest in each student.

Two parents particularly stressed the support they received from teachers when these teachers went out of their way to do something to help the family on their personal time—going over and beyond the call of duty. One parent described such an incident:

It was the first day of summer vacation and my son was off the wall, because he really needed structure. I was freaking out, and I couldn't deal with it. I called the teacher and told her I didn't know what to do. She came across town and took him to her house and said, "Do something fun for 2 hours."

This same parent also emphasized how much it meant to her when the teacher said, "I want to know, what you want your child to be able to do, because my goal is to make your life at home easier."

*Administrative Issues.* Next to teachers' concern about administrative issues was the second most frequently mentioned topic in chi school category. On the whole, the major theme of comments related to the struggle of dealing with administrators and administrative issues.

Families identified four administrative concerns. The first was lack of available resources. Several parents indicated that they would fre-

quently get comments from administrators such as, "We don't have the resources." Another parent mentioned her concern that her son was put in a harness on the school bus, because the school could not afford an aide.

The second concern was a push from administrators to place their child in a more restrictive setting. The rationale was usually that people in special education schools or classrooms "know what to do."

The third major concern pointed to a failure to implement fundamental requirements of the Individuals with Disabilities Education Act. The one participant whose primary language was Spanish expressed significantly more administrative concerns than did any other parent. She indicated that she had asked for an evaluation, but the school said that they did not have anyone who could do it. She said she had never seen an evaluation and did not know whether her daughter was in a general or special classroom or if her daughter had an individualized education program (IEP) or any other kind of written program. She didn't know what the instructional goals were or if any had been established. Having great fear that her daughter was being sexually abused by the bus driver, she had made a request to have her daughter moved to another school, but she had not heard from the school.

The fourth major problem was expressed by parents of a preschooler concerning administrative criteria for placement. Table 2 includes a quote from these parents describing their concern about the principal's initial input into the placement decision.

Parents expressed more concerns than praise for administrators. One family praised an administrator, stating that inclusion happened for their daughter because the principal had "set the tone for an accepting environment."

*Inclusion.* The term *inclusion* is often used to refer to many different arrangements. We define *school inclusion* as the practice of educating students with disabilities in neighborhood schools and general education classrooms by using flexible and individualized instructional methods and groupings (Gee, 1996; Thousand, Villa, & Nevin, 1994). Given that definition of inclusion, only two of the preschoolers met the criteria for being in an inclusive classroom. These two students were strongly supported by university faculty and student interns. Most of the elementary and secondary

students who had some kind of combined special/general education placement spent the majority of their time in a special education setting. Time spent in general classrooms was typically not more than 1.5 hr per day. Most of this time focused on being physically present in classrooms during nonacademic experiences.

Approximately one third of the parents of school-age students made some mention of *social interaction* between their son or daughter and schoolmates without a disability. Several parents said their child is physically present in the school but without social interaction. Two children, a preschooler and a high school student, had at least one *friend* at school. In some instances, parents had gone into the school to provide information to teachers, principals, and students about how best to interact with their child. A frequent comment from parents was the need to consider the other students in the school and to focus research on how to create benefits for them from inclusive experiences.

Families expressed a broad range of inclusion benefits; in order of frequency, these were benefits for the child, family, and others. The major benefit for the child was having good role models from whom children with problem behavior could learn. Families also mentioned that children tended to be happier, more confident, and more extroverted when they participated in general education classes and that inclusion at school could be a catalyst for inclusion in the community at large.

Very few benefits for other children were mentioned. One parent noted that the children in his daughter's class had pride in her accomplishments, and they enjoyed helping her with the computer. He felt strongly that inclusion would benefit members of society who do not have a disability, as well:

In California, one of the strongest cases for inclusion is that our state is very diverse. In order to live in the next century, we have to understand how to live with differences.

Interestingly, families noted these benefits, despite also emphasizing the significant need for administrators and teachers to be more fully pre-

pared to implement inclusion effectively. In addition, parents noted benefits even though the students with problem behavior were spending only a small portion of time in general education classes. A theme of the comments related to inclusion was that administrators and teachers did not necessarily need to "know how to do inclusion," but they did need to have an open, problem-solving attitude that solutions could be found by working collaboratively. Families of preschoolers and elementary students reported that inclusion seemed more feasible to them, as contrasted to families of secondary students.

Families also noted inclusion drawbacks. The major drawback was the time, energy, and frustration experienced by parents in working to create inclusive opportunities, particularly in schools. Families stated that many school administrators and teachers did not have the necessary training and so created many unnecessary roadblocks, because they did not want to move in this direction. Families realized that often inclusion required extraordinary advocacy on their part.

A different kind of drawback was mentioned by a parent whose child was attending a special school out of state. This parent commented, "I experience condemnation everywhere I turn." She stated:

The difficulty ... is that I go to all these meetings and everyone is pushing inclusion. These people are talking about having their child in their own homes and fighting the school system and they don't understand that for some people that is not possible.

One mother strongly emphasized the importance of taking the best of both worlds-inclusive and specialized-and the best of interactions with all kinds of people-both with and without disabilities. She cautioned against failing to identify the problems with inclusion:

I'm realistic enough to know that Dan needs to exclude himself at times so that he will not be excluded permanently.... Full inclusion is fine, but its not always fine for everybody.

Two major catalysts encouraged these families to pursue inclusion. Several parents had attended conferences and learned about the inclusion concept and were interested in pursuing it, but they

found difficulty in obtaining research information about the effectiveness of inclusion or strategies for helping to implement it on a daily basis. Several of the parents mentioned hearing Lou Brown talk and described his talk as being the "transforming event" that led them to pursue inclusion. They adopted an inclusion ideology, and they then started talking with their school district administrators. At least half of the families saw themselves as the only catalyst for inclusion, and, they expressed frustration in having to work so hard to obtain it, particularly in having to deal with their own fears and concerns about dangerous and difficult behavior (Turnbull, A. P., & Ruef, in press), as well as those of administrators, teachers, other parents, and classmates.

The other major inclusion catalyst involved families living in a university community and having access to faculty members who were current in research and best practice and willing to be side-by-side advocates with them in IEP conferences. A couple of families who lived close to a university identified faculty as being instrumental to their child's inclusion.

#### *Inclusive Lifestyle Issues Associated with Community Participation*

Families paid much less attention to issues associated with engaging in activities in community settings other than school. The three people with problem behavior (all adults) who most actively participated in the community had friends and engaged in community activities primarily with their friends. Thus, families gave lower priority to community inclusion, not because families thought it unimportant, but because of time and energy limitations; unavailability of other companionship; and family and others' perceptions of worry, fear, and embarrassment about problem behavior (Turnbull, A. P., & Ruef, in press).

Approximately one third of the families mentioned participating in at least one community activity: shopping, clubs (e.g., swim club, health club), and recreational settings (e.g., YMCA, bowling alleys). Families identified several strategies as helping foster community participation, including having a companion to support the person; having a car that the companion could drive; having the companion go along with families on recreational outings; encouraging the individual with problem behavior to participate in a special-populations

recreational program; and learning, as a family, to minimize their own worry, fear, and embarrassment about problem behavior in public and learning to 'ignore others' stares and disapproving reactions.

Several families pointed out the importance of inclusive school experiences as a catalyst for expanded opportunity to participate in the community. Because children and youth had instruction in school that was carried out in community settings or that generalized to community settings, families then could participate in those same community activities with their child, because of the child's enhanced competence. Interestingly, when children could participate in the community, then the family could do likewise and avoid being so isolated themselves. One parent commented:

Now we're able to go bowling with our family. At Christmas time our 4-H Club had a party at the bowling alley, and because Patrick knows what to do at the bowling alley, he was quite able to do that party with us. He uses a ramp. They have a snack bar there, and he knows about getting and eating snacks at the bowling alley, where to sit, what to do, and not to grab others' food or drinks.

#### *Inclusive Lifestyle Issues Associated with Supported Living and Supported Employment*

Several families addressed inclusive lifestyle issues associated with supported living and supported employment.

*Supported Living.* Four of the people with problem behavior were over 21 years of age. Three had lived in a group home, and one was living with his family. Of the three who had experienced a group home, two had left that arrangement and were living in innovative supported living situations primarily initiated and implemented by their families.

Two families set up innovative supported living arrangements. One of these represented a comprehensive lifestyle change for Rob, 36, who had been living in a group home, where he had experienced a great deal of frustration and isolation. After intense advocacy with the group home staff and state officials, Rob's mother was finally able to arrange funding for Rob to share a home of his own

with Mark, a close friend and roommate of his choice. Mark had been one of the support people in Rob's group home for several years and had developed a "connection" with him. Both Mark and Rob were eager to live together. The "Supported Living" category in Table 2 includes Mark's description of their living arrangement.

*Supported Employment.* None of the four adults with problem behavior had a paid job. Of the four adults, three were in day programs, and one was doing volunteer work for a limited number of hours each week. Families characterized the day programs as highly ineffective and unproductive.

Three parents stressed the importance of their son or daughter's getting a job and having support to do the job; one parent reported that she believes that "jobs are only for higher functioning kids" and that her son would not be capable of this. Three of the four families have actively advocated for housing support, and they implied that they had not addressed employment because of the amount of time they were investing in housing advocacy. None reported having *any* adult agency services that provide supported or competitive employment options.

## **DISCUSSION**

This investigation has raised a host of troubling issues about the scant and tenuous inclusive lifestyle supports that are available for these 17 families who have sons and daughters with problem behavior. Although the findings related to family life, Friendships, schools, community inclusion, and supported living/supported employment have generally confirmed challenges that people with problem behavior face in these areas, the unique contribution of the findings is that they provide a "Family voice" to these challenges and issues. The overall theme of these voices is that family members must be the initiators, catalysts, and choreographers of attaining inclusive life-style supports when a family member has problem behavior. Families want more genuine help-professionals and community members working with them collaboratively-to address complex challenges across a broad number of life domains and environments. One of the underlying messages is that families want professionals to "do their job: in a state-

of-the-art, collaborative, and empowered way. These professionals include people employed by the service system designed to provide free appropriate public education (including special education and related services), transitional planning, supported employment, supported living, and community inclusion. Families want to be partners, but they do not want to have to spend so much time being change agents.

#### *Actualization of Inclusive Lifestyles*

We have defined *inclusive lifestyle*, especially as it pertains to people with problem behavior, as follows: Pervasive participation in family, friendships, school, work, and community life consistent with one's preferences and characterized by responsive and reciprocal supports.

Given that definition, of the 17 people with problem behavior represented by the families we interviewed, how many have attained an inclusive lifestyle? Although we were awed by the extraordinary lengths to which so many of these families have gone to get inclusive lifestyle supports and services, none of the families described their situation as characterizing the attainment of a fully inclusive lifestyle for their family member with problem behavior.

#### *Pervasive Themes*

The most pervasive theme of these interviews is that families themselves have been the catalyst in most situations when any positive action has occurred related to attaining inclusive lifestyle supports. A corollary to that theme is that the majority of families express exhaustion and frustration in always needing to instigate and choreograph inclusive lifestyle change.

Although the families themselves were the primary "movers and shakers" for implementing inclusive lifestyle supports, typically the families had no regular and convenient access to state-of-the-art information, particularly the substantial and growing body of literature on positive behavioral support. Other themes that appeared on each of the focal areas of interest are as follows:

*Family Life.* Many people erroneously assume that siblings and extended family will naturally understand the needs of a family member with

problem behavior and be readily available resources to parents. There has been far more emphasis placed in the developmental disability field on establishing relationships between children with disabilities and their classmates at school as contrasted to emphasizing emotionally connected relationships with siblings and extended family. Building cohesive and reciprocal family relationships from the earliest years forward will likely be a major contributor to an inclusive lifestyle.

Other important needs include practical information to help families with home routines, such as mealtime and sleep. The importance of preparation of child care, respite, and support providers was strongly underscored by families, as well as the availability of cash subsidies to pay for these services (Herman, 1994). When we consider the opportunities for paid staff to have time away when they are working closely' with people with problem behavior and then consider one of the families in this study who has had only one night away in 11 years, we begin to see imbalances in the allocation of resources to prevent burnout. Professionals and families committed to people with problem behavior need to collaborate more extensively with policymakers, families, and service providers who are developing statewide Family support programs to ensure participation and appropriate services for these families (Bradley, Knoll, & Agosta, 1993; Turnbull, H. R., Barber, & Garlow, 1991).

The emphasis that many families place on participating in their religious community and the lack of ability to do so raises an important issue for future consideration. Religious organizations have the potential of offering many different supports to families, including spiritual values and faith, social support, and activities for the individual with problem behavior, social support for parents, and assistance in accessing other community resources (Fewell, 1986; Weisner, Belzer, & Stolze, 1991). Special and general educators can be key resources in preparing religious organization instructional personnel in creating personalized supports. The LEP conference may be a time-efficient forum for sharing relevant instructional information with them (Turbiville, Turnbull, Garland, & Lee, 1996).

*Friendships.* There is an obvious *glaring void* of friendships in the lives of people with problem behavior. There has been a great deal of confusion on the appropriateness and inappropriateness of staff forming emotional connections, as well as confusion about when it is appropriate to pay and not pay staff who spend time outside of work with people with a disability, especially as friendships begin to evolve.

There is a vast need to concentrate much more directly and from the earliest ages possible on the development of emotional connections and friendships for people with problem behavior. The emerging efforts on social relationships have been directed more at having people participate in activities together rather than on investigating ways to help people connect in a way that forges an emotional bond of commitment, mutuality, and reciprocity.

We recommend that much stronger attention be given to understanding the components of friendship (Berndt, 1989; Reid, Landesman, Treder, & Jaccard, 19'89) and focusing on the "chemistry" of connection (Grenot-Schoyer, 1994; Panacek-Howell, 1994; Staub, Schwartz, Gallucci, & Peck, 1994; Van der Klift & Kunc, 1994). One of the best ways to do this is to learn from students and adults with problem behavior who have formed mutual and reciprocal friendships.

*Schools.* Most of the families have invested substantial time and effort in trying to inform teachers, administrators, and peers, about how best to support their son or daughter. Although these parents seem to be willing to assume this role, several of them indicated how they would have welcomed the educators' taking more initiative. They expressed exhaustion and frustration over the incessant work of being a change agent and relationship facilitator.

The data suggest a strong family concern about administrator and teacher competency in providing an appropriate education for their children with problem behavior (Erwin & Soodak, 1995; Hasazi et al., 1994). Parents reported that they needed to have information that they could use to convince their school systems about the efficacy of state-of-the-art approaches and to urge them to move ahead with staff development. More research is needed on best educational practices for students with problem

behavior, and information needs to be organized in a way easily accessible to families, teachers, and administrators (Meyer & Evans, 1993).

There are significant implications for personnel programs that prepare teachers to provide inclusive lifestyle supports for students with problem behavior (Ferguson, Meyer, Jeanchild, Juniper, & Zingo, 1992). In addition to administrators and teachers having the instructional competency, parents also stress the need for professional empowerment to instigate and implement systemic changes associated with school reform that will be necessary if inclusive lifestyle supports are, indeed, to become reality (Sailor, Gee, & Karasoff, 1993; Thousand et al., 1994; Villa & Thousand, 1995).

*Community Inclusion.* Far too few opportunities exist for people with problem behavior to actively participate in communities and to have relationships with people throughout the community. Families often feel that they are the only socialization agent; and they must continually confront their own fear and worry about problem behavior in public, as well as the unwelcome reactions of many community citizens (Turnbull, A. P., & Ruef, in press). This critical area of inclusion warrants far more attention, and families are eager to receive support in making community inclusion a reality. They particularly want friends and companions with whom their son or daughter can experience community activities. They also believe the responsibility for community education should be shared broadly and not fall solely to them.

*Supported Living and Supported Employment.* Two families in the study were developing an innovative approach to supported living, although in each situation they were primarily using common sense as a guide, rather than having access to any state-of-the-art models and materials. Parents underscored a strong need for information on housing-particularly innovative supported living arrangements with specific guidelines for finding roommates, other support persons, funding, and short- and long-term arrangements for supervision and monitoring. In addition, policymakers and community agency administrators need to know more about innovative supported living arrangements so that they might be able to take more initiative in

creating these options; and teachers need to know more so that they can prepare students during elementary and secondary years with critical skills to enhance the likelihood of their adult success.

Of all groups of people with disabilities, people with problem behavior likely have some of the greatest challenges in getting and maintaining employment (Kregel & Wehman, 1989; Smith & Belcher, 1994). The lack of employment causes great stress and worry for families. Creating greater employment opportunities for this population is a high priority, as is research and best practice information for families and teachers about how best to prepare people during the elementary and secondary years for successful employment. Such information is available (Ponthieu, Jones, Williamson, & Beaird, 1994; Smith, 1994), but unfortunately it is not being implemented nearly as comprehensively or as early as is needed. Will's (1984) decade-old commitment to a job's being the implied promise of special education needs to be put into practice for people with problem behavior.

#### IMPLICATIONS FOR PRACTICE

After the mother of an adult who participated in the interviews had an opportunity to read the full manuscript, she responded as follows:

I felt a tremendous sadness after I read this draft. My son is 29 years old, and it hurts me so to realize that parents today are living through what I did over 25 years ago. There is not enough parent support.... Parents are struggling on their own not just addressing their child's behavior problems, but there is a variety of concerns. And what's more disturbing is the fact that only 17 parents were interviewed. Aren't there hundreds more out there with a variety of concerns? ... I can identify with these parents. I know how emotionally draining it is to raise a handicapped child. I know how helpless you feel in trying to do the impossible on a daily basis. You're untrained and unskilled to meet the enormous needs of your child; but, boy, do you try even when you don't sleep enough or eat your "balanced" meals. You live with the fears, frustrations, and lots of sacrifices, but you just never give up. For this is your child, and the love and commitment will see you through. Parents need support and encouragement.

The challenge to the field is to create the collaborative linkages among all stakeholders—families, people with problem behavior, friends, teachers, administrators, religious organization personnel, community citizens, landlords, roommates, neighbors, bosses, and co-workers—to embrace the complexity of inclusive lifestyle options and to invent new supports and services to translate this vision into reality.

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Manuscript received March 1995; revision accepted February 1996.

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